

**The development and evaluation of positive psychology outcome  
measures for older adults with dementia**

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## **Declaration**

I, Charlotte Rose Stoner, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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## **Abstract**

### **Background**

Positive psychology refers to the scientific study of strengths and capabilities that contribute to wellbeing. It can be considered an asset-based to dementia but is currently limited to the qualitative literature with no means of quantitatively documenting positive psychology concepts in dementia.

### **Aims**

a) To explore dementia, from a positive psychology perspective; b) to develop and evaluate robust outcome measures representing positive psychology in dementia; c) to validate an additional outcome measure of positive psychology for people with dementia.

### **Methods**

Using a qualitative study (n =18) and expert feedback, items were generated for two outcome measures. The measures were subject to an internal pilot (n =33) and then evaluated in a large-scale study (n =216). Within this study, an additional measure (Control, Autonomy, Self-realisation and Pleasure Scale; CASP-19) was validated. Following this, psychometric testing was conducted. Responsiveness to change was assessed within an additional study (n =21) and structural equation modelling techniques were used in a secondary analysis of the combined samples (n =237) to explore how characteristics of participants affected positive psychology concepts.

### **Results**

Items were generated for two measures: The Engagement and Independence in Dementia Questionnaire (EID-Q) and the Positive Psychology Outcome Measure (PPOM). Internal piloting indicated adequate psychometric properties with minor amendments to items. In-depth analysis of both measures and the CASP-19 indicated adequate psychometric properties and factor solutions were evidenced but

responsiveness could not be established. Demographic and clinical characteristics did not affect levels of positive psychology but relationships were evidenced for quality of life and depression.

### **Conclusions**

On a theoretical and clinical level evidence here suggests people with dementia are able to accurately explore these concepts and make complex self-judgements. On a research level, outcome measures developed and validated may assist with the development of asset-based approaches and interventions for dementia.

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## Glossary and abbreviations

$\alpha$	Cronbach Alpha – Internal consistency analysis
ADL	Activities of Daily Living
ANCOVA	Analysis of Co-variance
ANOVA	Analysis of Variance
CASP-19	Control, Autonomy, Self-realisation and Pleasure Scale
CDR	Clinical Dementia Rating Scale
CD-RISC	Connor-Davidson Resilience Scale
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
df	Degrees of freedom
DSM-IV	Diagnosis and Statistical Manual of Mental Disorders (4th edition)
EFA	Exploratory Factor Analysis
EID-Q	Engagement and Independence in Dementia Questionnaire
GDS	Geriatric Depression Scale
GFI	Goodness of Fit Index
HHI	Herth Hope Index
M	Mean
MBCT	Mindfulness Based Cognitive Therapy – research study
MMSE	Mini Mental State Examination
n	Number of participants
NELFT	North East London NHS Foundation Trust
NFI	Normal Fit Index
NHS	National Health Service
NICE	The National Institute for Health and Clinical Excellence
NIHR	National Institute for Health Research
$p$	Level of significance
PHQ-9	Patient Health Questionnaire
PP	Positive Psychology
PPI	Patient and Public Involvement
PPOM	Positive Psychology Outcome Measure
PPOM	Positive Psychology Outcome Measures for people with dementia – NIHR research study
PRIDE	‘Promoting Independence in Dementia’ - NIHR research study
PwD	Person/ People living with dementia
QoL	Quality of life

QoL-AD	Quality of Life in Alzheimer's Disease Scale
$r$	Pearson's correlation coefficient
R	Effect size
$R^2$	R squared (coefficient of determination)
REC	Research Ethics Committee
RMSEA	Root mean square error of approximation
SD	Standard deviation
SE	Standard error
SEM	Structural Equation Modelling
SPSS	Statistical Package for the Social Sciences
SRMR	Standardised Root Mean Square Residual
TAU	Treatment as usual
UK	United Kingdom
US	United States
$\chi^2$	Pearson's Chi-square test



# **1. An introduction to dementia, positive psychology and outcome measurement**

## **1.1 Dementia**

Dementia is characterised by a loss of cognitive function within short and long-term memory that impacts upon a person's daily functioning. To be diagnosed with dementia, an individual must display multiple cognitive deficits including memory impairment and at least one of the following symptoms: aphasia, apraxia, agnosia or disturbance in executive functioning. Impairments are also noted in social or occupational functioning (American Psychiatric Association, 1994). Common dementias include Alzheimer's disease, which accounts for approximately two thirds of cases, vascular dementia, dementia of mixed aetiology (Alzheimer's disease and vascular dementia), Pick's disease and Parkinson's related dementia.

Currently, there are 835,000 people living with dementia in the United Kingdom and, as the population ages, this number is set to increase to over a million by 2025 (Alzheimer's Society, 2014). Worldwide, there are an estimated 46.8 million people living with dementia, and the estimated global cost of dementia was US\$818 billion in 2015. During 2015, 9.9 million people were diagnosed with dementia, equating to one person every three seconds (Alzheimer's Disease International, 2015). The impact of dementia has been described as a growing global challenge and people with dementia can experience undue hospital admissions, loneliness and fear (Department of Health, 2015).

### ***1.1.1 Psychological and Social Models of Dementia***

Whilst the term dementia has been noted throughout history, beginning with its use in the writings of philosophers from the Hellenistic Empire, its conceptualisation has

somewhat changed from its origin of senile dementia to the broad range of disorders under the umbrella term of dementia seen today (Boller & Forbes, 1998). Historically, dementia has been characterised as a medical disease and this conceptualisation has led to a predominantly pathology based model being utilised in assessing and treating those with dementia (Berrios, 1990). As such, the psychology of dementia has generally been constructed in terms of progressive deficits, negative aspects of behaviour or mood and progressive dependency. This medical conceptualisation has led to the dominance of a pathological, loss-oriented model in dementia research and care (Lyman, 1989). Such a conceptualisation has resulted in a stigma surrounding dementia as a debilitating condition, for which there is little to offer (Vernooij-Dassen, et al., 2005). Furthermore, this stigma can result in the misconception that people with dementia have poor quality of life or lack the capacity for pleasure (Graham, et al., 2003).

However, several other models of dementia have been theorised including the social model, dialectical model and more recently the biopsychosocial model. Often, within the context of a social model, dementia is regarded as a disability in which this disability is not intrinsic to the individual but is an outcome produced by social processes of exclusion (Marshall, 2004). From this perspective, people with dementia have impairments but their disability results from their treatment or exclusion by society. This model appears to be less reductionist than a pure medical model of dementia, as it seeks to understand emotions and behaviours of a person with dementia by placing them in the context of their social circumstances (National Institute for Clinical Excellence, 2007). Subsequent theories have attempted to bridge the gap between a medical and social model, including Kitwood's dialectical model, which emphasises the interrelationship between cognitive impairments, psychological and social factors (Kitwood, 1993). The more recent biopsychosocial model of dementia

(Spector & Orrell, 2010) goes further by disaggregating biological and psychosocial factors, suggesting that each domain consists of fixed and tractable factors.

Psychosocial fixed factors include education and previous life events, whereas biological fixed factors include age and genetic factors. Psychosocial tractable factors include mood and environment, whereas biological tractable factors include physical health and sensory impairment. Spector and Orrell (2010) proposed a model that presents dementia as a process beginning with early organic change and moving towards diagnosis, institutionalisation and finally death. The incorporation of both biological and psychosocial factors has resulted in a highly individualistic model that can be used to formulate cases of individuals with dementia (Figure 1.1). Evidence for adopting this framework into standard practice has been found in a number of studies such as that by Clare et al., (2012).

## **1.2 The Psychology of Old Age and Dementia**

Traditionally, the psychology of old age and dementia has been one of decline and progressive dependency, characterised by disengagement and despondency. Examples include the conflict of generativity vs. stagnation and ego-integrity vs. despair (Erikson, 1968) and Disengagement Theory, which views ageing as the 'inevitable, mutual withdrawal or disengagement, resulting in decreased interaction between the ageing person and others in the social system he belongs to' (Cumming & Henry, 1961, p. 227). However, since this, efforts have been made to explore old age from a more balanced perspective. Examples of more recent models of old age and their relation to dementia are presented here.

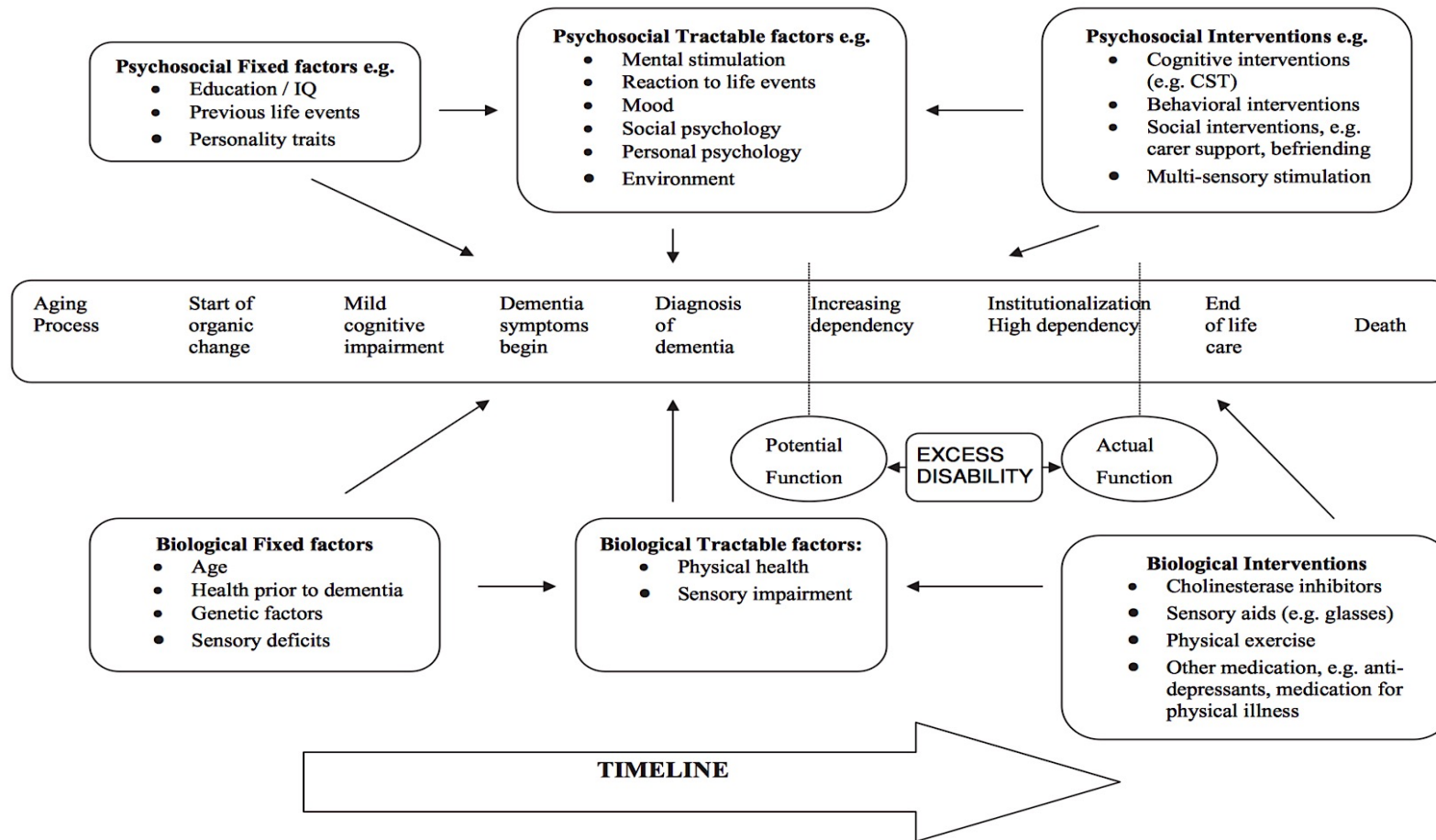
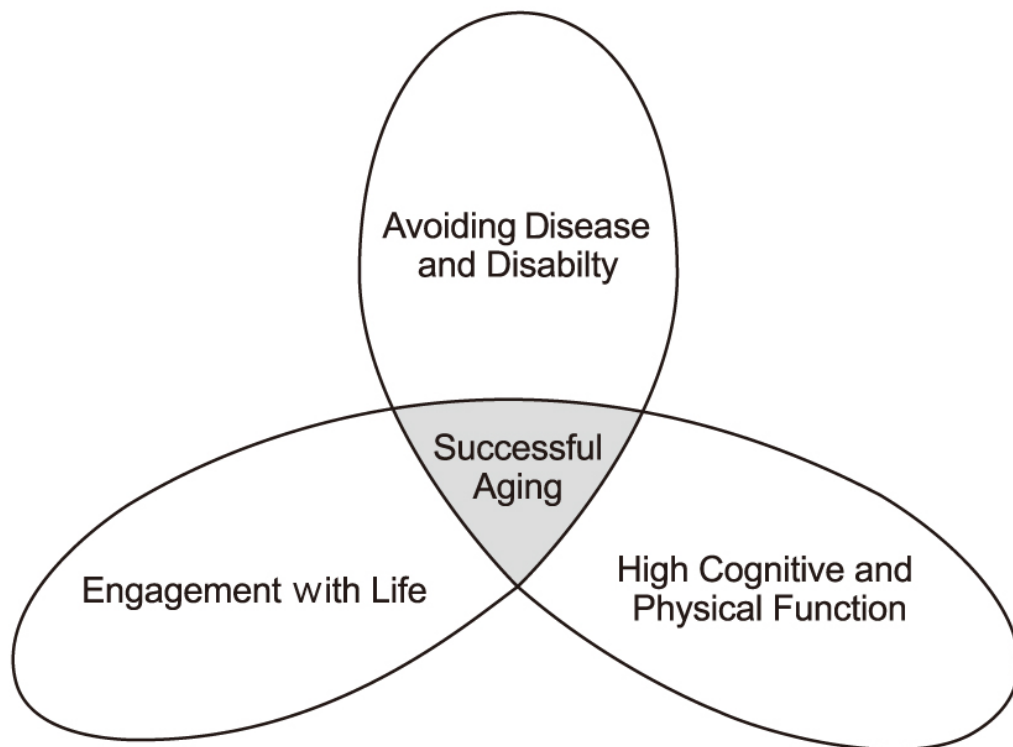


Figure 1.1 The Biopsychosocial model of dementia (Spector & Orrell, 2010)

### 1.2.1 Successful ageing

The notion of successful ageing (Figure 1.2) is not without contention. Whilst the term has been in use for at least fifty years, no consensus as to a universal definition has been reached. The definition of ageing successfully, which is most commonly used, consists of the satisfaction of three domains: An individual has a low probability of disease and disease related disability, has high cognitive and physical functional capacity and is actively engaged with life (Rowe & Kahn, 1997). Each of these conditions contains subparts. For example, the low probability of disease refers also to the severity of risk factors for a disease. Furthermore, whilst physical and cognitive functioning refers to what an individual is capable of, engagement with life refers to interpersonal relationships and productive activity i.e. what they engage in.



*Figure 1.2 Model of successful ageing (Rowe & Kahn, 1997)*

Since its introduction, a number of alternative models have been proposed including calls for social factors within the definition (Riley, 1999) and the model has been

subject to increasing levels of criticism. Criticisms include the lack of subjective and individual components and the cultural bias of a westernised view of ageing (Martinson & Berridge, 2015). However, the most in-depth and substantial criticism is around the concept of blame, and this is particularly appropriate for individuals with dementia. If a person with dementia is said to have failed to aged successfully, there is the potential to assign blame to these individuals, which in turn, may lead to stigma and discrimination. Furthermore, ageing unsuccessfully is a difficult concept to apply to older adults, who often live with at least one chronic health condition. This is supported by a large longitudinal study, of which 43% of older adults living with one chronic health condition and 35% of participants with two more or more chronic conditions identified themselves as having aged successfully (Strawbridge, Wallhagen, & Cohen, 2002). It is, therefore, a problematic model for people with dementia.

### ***1.2.2 Gerotranscendence***

Gerotranscendence describes a process of increased life satisfaction, reduced self-occupation and a heightened sense of affinity with others and occurs along three dimensions: the cosmic dimension, the dimension of self and the social dimension. The cosmic dimension refers to the experience of time being redefined, with past and present experienced as one. The dimension of the self refers to an increase in outward looking perception and decreased self-centredness. Finally, the social dimension refers to an increased satisfaction with valued relationships and a relaxation in superficial socialising (Tornstam, 2011). Whilst Tornstam (2011) did not expand his theory to dementia, he noted that people both with and without dementia experienced the transcendence of time borders (between past and present), suggesting that the process may not differ for people with dementia. Furthermore, whilst previously it was thought that being cognitively intact was a prerequisite for transcendence, evidence suggests

that people with dementia are able to undergo this transcendence (MacKinlay & Trevitt, 2012).

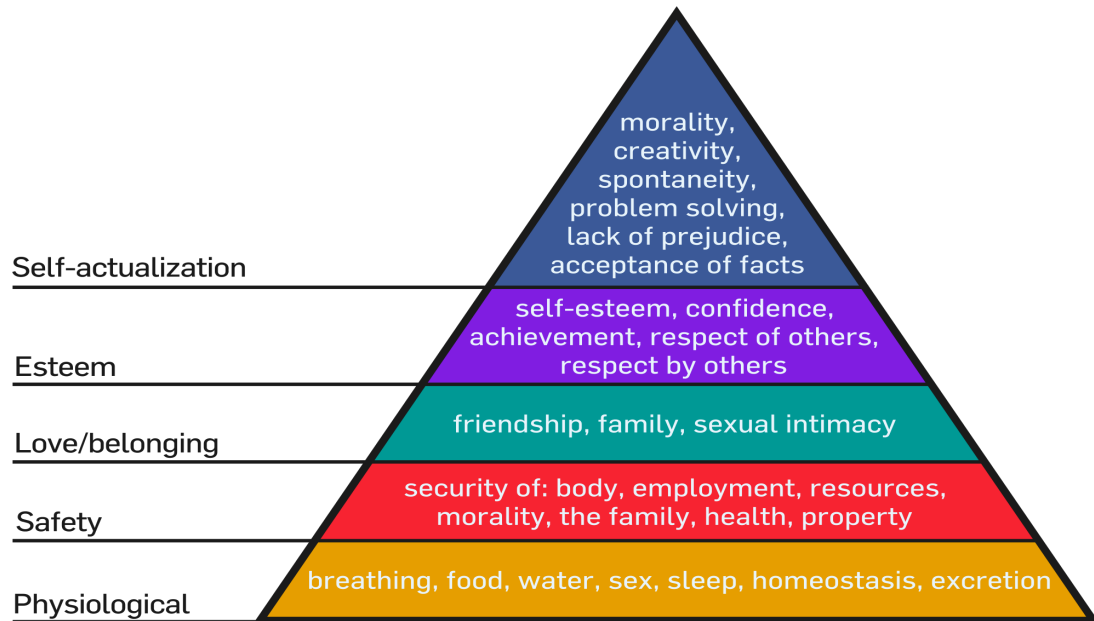
## **1.2 A New Approach: Positive Psychology**

Traditional models of old age and dementia, as discussed above, tend to approach the subject from a negative view-point. Or, in the case of gerotranscendence, applications to dementia are overlooked. Therefore, a new approach is needed to ensure that research and practice reflect a more balanced view of dementia, in which concepts that contribute to wellbeing, and wellbeing itself, are evidenced in an empirically sound manner. Such an approach is within the confines of positive psychology theory.

### ***1.2.1 History of Positive Psychology***

The term positive psychology originated in humanistic psychology and was coined by Maslow (1954). Humanistic psychology was developed in response to the preceding theories of behaviourism, in which free will was viewed as an illusion and that human behaviour was largely dependent on the consequences of previous actions (Skinner, 1938). In contrast, humanistic psychology was concerned with how one's behaviour was determined by one's perception of the world and its meanings, and posited that people are not solely the product of their environment. Furthermore, humanist psychologists such as Abraham Maslow and Carl Rogers theorised that people are intrinsically motivated to fulfil their potential in order to achieve self-actualisation. Maslow's (1943) theory of human motivation stipulated that individuals were essentially positive and were motivated by five hierarchical needs. He suggested that these needs begin with physiological needs before progressing to safety, love or belonging, esteem and culminating in self-actualisation. This epitome of motivation

incorporates characteristics such as morality, creativity, spontaneity and acceptance of facts and is deemed to be the pinnacle point of human development (Figure 1.3).



*Figure 1.3 Maslow (1943) hierarchy of needs*

Whilst earlier research including studies of gifted children (Terman, 1919) and man's search for meaning (Jung, 1933) could be considered positive in nature from the humanist perspective, the study of such concepts has largely been confined to specialist areas. Instead, in recent years, the empirical focus of mainstream psychology has been in 'curing' mental illness. Whilst this has led to many benefits for assessing and treating mental illness, the assessment of positive concepts including actualisation, wellbeing and love appear to have taken a back seat. This was summarised by Maslow (1954, p.354), who stated that 'the science of psychology has been far more successful on the negative than on the positive side; it has revealed to us much about man's shortcomings, his illnesses, his sins, but little about his potentialities, his virtues, his achievable aspirations, or his full psychological height. It is as if psychology had voluntarily restricted itself to only half its rightful jurisdiction, and that the darker, meaner half'.



### ***1.2.2 The Reintroduction of Positive Psychology***

Martin Seligman introduced positive psychology as an individual branch of psychology and specialist discipline in his American Psychiatric Association (APA) presidential address, in which he discussed the importance of documenting what actions lead to wellbeing, positive individuals and communities in an empirically sound manner (Seligman, 1998). Building on humanist theories, he characterised this as a re-introduction of positive psychology to ‘catalyze a change in the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities’ (Seligman & Csikszentmihalyi, 2000, p. 5). However, the focus on scientific methodology illustrated a clear differentiation between Seligman’s positive psychology and humanistic positive psychology, the latter of which preferred to use individualised phenomenological approaches.

Seligman’s positive psychology is a non-pathologising approach to mental health, recognising that there is often a dynamic interplay between positive and negative psychological processes and outcomes. It is an applied approach that is intended to supplement, rather than replace, what is known about suffering or disorder. In this way, the approach does not attempt to deny negative experiences or emotions but seeks to examine and understand how people might attempt to live well or flourish, despite challenges encountered over a life span (Lomas & Ivztan, 2016).

Since Seligman’s APA address, positive psychology has gained credence, with a number of definitions as to what constitutes ‘positive psychology’ being proposed. These include: valued subjective experiences that contribute to wellbeing, contentment and satisfaction in the past, hope and optimism for the future and flow and happiness in

the present (Seligman & Csikszentmihalyi, 2000) and the study of conditions and processes that contribute to optimal functioning of people, groups and institutions (Gable & Haidt, 2005). The most common and most cited definition that forms the basis of this thesis is that positive psychology is an umbrella term for the study of positive emotions and positive character traits that enable individuals, communities and organisations to thrive (Seligman, Steen, Park, & Peterson, 2005).

### ***1.2.3 Positive psychology models and frameworks***

In addition to the number of definitions of positive psychology that have been proposed, a number of models and frameworks, displaying differing characteristics and processes that underlie positive psychology have also been proposed. A brief overview of these frameworks and models are presented here.

#### ***1.2.3.1 Domains of Psychological Wellbeing***

Stemming from humanist principles, the Domains of Psychological Wellbeing (Ryff, 1989) emerged nine years prior to the introduction of positive psychology as a specialist branch, also as a critique of the negative and one-dimensional conceptualisations of wellbeing. It follows a eudaemonic model of wellbeing and theorises wellbeing as consisting of six domains: Self-acceptance, positive relations with others, autonomy, purpose in life and personal growth. Participants are either classed as high or low scorers for each of these domains. For example, a high scorer in self-acceptance is reported to possess a positive attitude toward the self; acknowledges and accepts the multiple aspects of self, including good and bad qualities; feels positive about the past self. Conversely, a lower scorer would feel dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities and wishes to be different than what they are (Ryff & Keyes, 1995).

### *1.2.3.2 Values in Action (VIA)*

In addition to his definition, Seligman and colleagues presented the VIA model (Figure 1.4), sometimes referred to as character strengths and virtues and published as a book (Peterson & Seligman, 2004). This book represented a significant effort to provide a common language or consensual nomenclature for the common core capacities of individuals. Based on a three-year project involving 55 social scientists, Peterson and Seligman (2004) drew on writings from Greek philosophers, major world religions and other notable figures to provide a descriptive list of 24 character strengths across cultures, nations and belief systems (Dahlskaar, Peterson & Seligman, 2005).

Strengths were classified as such using 10 criteria including the contribution to various fulfilments that constitute a good life, the strength is morally valued in its own right and the display of this strength does not diminish others. These 24 character strengths were categorised into six sets of universal virtues: transcendence, temperance, justice, humanity, courage and wisdom. Such character strengths and virtues can be deemed universal and have been evidenced in remote areas such as the North Pole (Biswas-Diener, 2006) and are similar across 54 countries (Park, Peterson & Seligman, 2006).

### *1.2.3.3 Positive Emotion, Engagement, Relationships, Meaning, Accomplishment (PERMA)*

Whilst the above VIA model provides a descriptive list of positive concepts that constitute positive psychology, the interaction between these concepts, their measurement and how they each relate to wellbeing was not described.

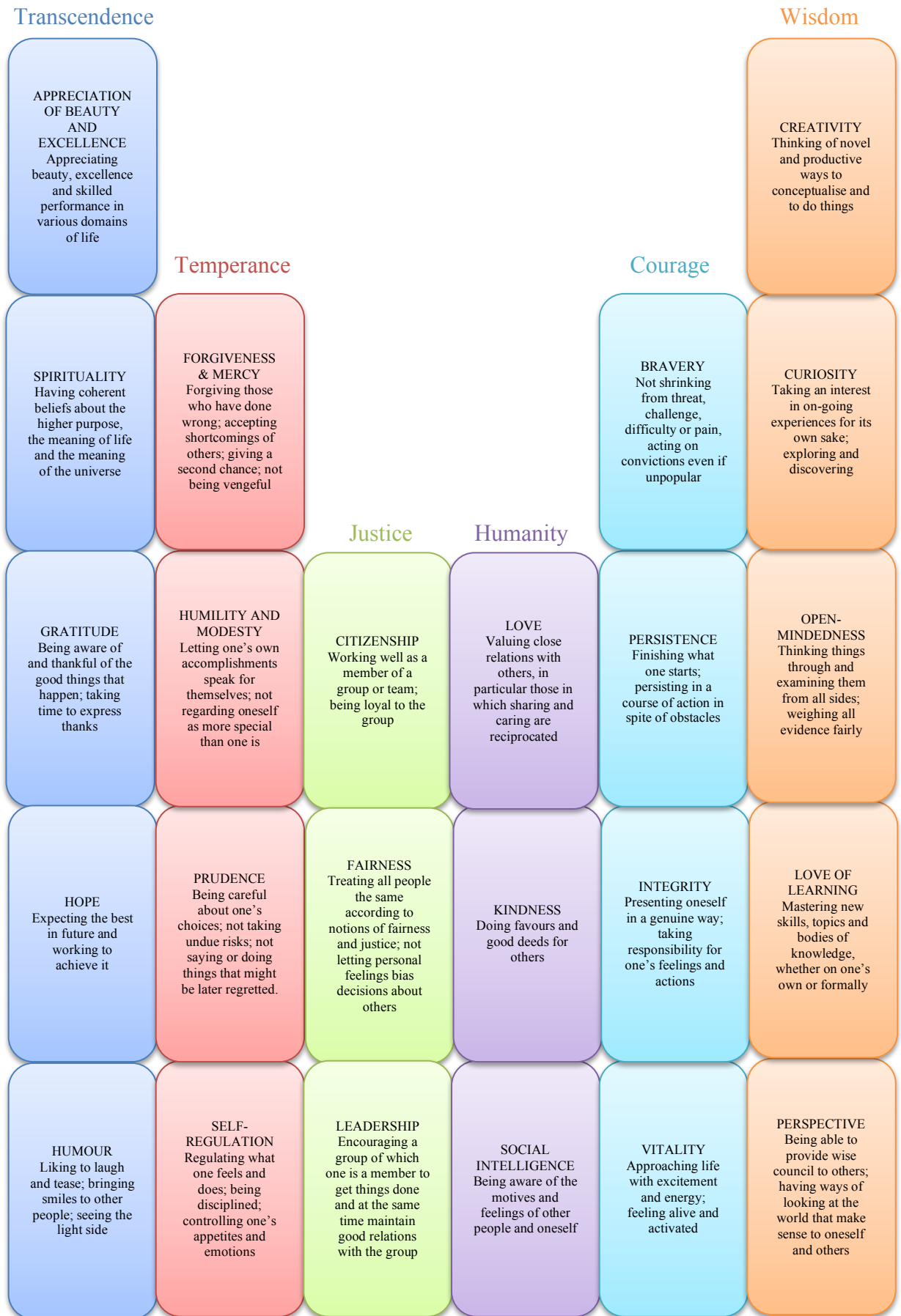


Figure 1.4 Character Strengths and Virtues (VIA; Peterson & Seligman, 2004)

To address this PERMA (Seligman, 2011) was proposed, which defines wellbeing as the satisfaction of five measureable domains: positive emotion (feeling joy or contentment), engagement with activity (flow), positive relationships (socially integrated, cared about and supported by others), meaning (purpose and connection with something greater than oneself) and accomplishment (feeling capable of daily activities, sense of achievements). Combined, these domains are termed ‘flourishing’ and are generally used as a measure of positive outcome. PERMA suggests that wellbeing is multidimensional and that the domains in question should be treated as a spectrum. This contrasts with other models, which view the absence of certain factors as a contributor to unhappiness or mental illness. PERMA also expands on the VIA model as more attention is paid to social factors, situational factors and the interaction of individual resources and relationships.

#### *1.2.3.4 Engine of Wellbeing Framework*

Expanding on PERMA, the Engine of Wellbeing Framework was developed to examine the inputs, processes and outcomes that contribute to both positive concepts and positive outcomes including wellbeing. Input variables are theorised to be either exogenous, which includes income, education and genetics, or endogenous, which includes personality traits such as optimism, neuroticism, curiosity and abiding values. Process variables refer to the internal states that influence decisions and choices an individual makes and follows a self-regulatory model (Carver & Sheier, 1981), in which an individual is said to engage in activities to achieve their goals. The outcome variables refer to voluntary behaviours that characterise wellbeing and usually consist of positive relationships, positive accomplishment, engagement in love or work, autonomous behaviour and activity (Jayawickreme, Forgeard, & Seligman, 2012).

Furthermore, wellbeing is defined as outcomes that people, free from coercion, would choose to do for their own sake and should satisfy the following conditions:

- i) The outcome contributes to a life well lived.
- ii) Outcomes can be pursued for their own sake.
- iii) Outcomes are defined and measured independently of other outcomes.

### ***1.3 Positive Psychology and Dementia***

Research into dementia has, in the past, tended to focus on models of deficits and losses associated with the condition, as well as behavioural challenges that professionals and carers face (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005). However, more recent initiatives such as the National Dementia Strategy (Department of Health, 2009) and the most recent ‘Prime Minister’s Challenge on Dementia 2020’ (Department of Health, 2015) call for the direct involvement of those living with dementia and for research into interventions that aim to maintain and promote quality of life. Due to these proposals, living well with dementia has led to a heightened interest in how society can support those living with the condition.

There is now a growing body of literature in relation to assessing quality of life for people with dementia. Whilst quality of life has long been recognised as a desirable outcome (Gibson, Carter, Helmes, & Edberg, 2010), the term is not without contention. It has been proposed that quality of life is an ideological concept and, as it is conceptualised by a healthy population, it is bound to the norms and values of this population (Jennings, 2000). Furthermore, it has been suggested that below a certain level of cognitive function, it is difficult for people with dementia to accurately appraise their quality of life (Moyle, Gracia, Murfield, Griffiths, & Venturato, 2011) and, as quality of life is a highly subjective concept, it is debatable as to whether proxy or

observational measures of this concept truly reflect an individual's appraisal of their own quality of life (Thorgrimsen, et al., 2003). Similar issues complicate the related assessment of positive psychology ratings with people with dementia, which are likely to require more challenging appraisals than quality of life. However, there are so few studies in positive psychology and dementia that further evidence is needed before a definitive statement can be made.

It is suggested that the shift to measuring 'quality of life' is the first step in a long process of recognising the positive states and emotions that people with dementia experience and measuring such positive states in a scientifically robust manner. Whilst quality of life research has contributed to a wealth of understanding, it is a term that is quite abstract in nature. A focus on more clearly defined positive strengths can only contribute to what is known of well-being.

### ***1.3.1 Positive Experiences in Dementia***

#### *1.3.1.1 Positive experiences in caregiving, relational care and 'The Senses Framework'*

Positive psychology research within dementia has tended to focus on carers of those with dementia. For example, a recent systematic review of positive outcome measures used for carers (Stansfeld et al., 2017), an assessment of self-efficacy in relation to health-related quality of life (Crellin, Charlesworth, & Orrell, 2014) and resilience within carers with relation to aggression in people with Alzheimer's disease (Wilks, Little, Gough, & Spurlock, 2011). However, there is now a growing body of research that indicates people who care for someone living with dementia on an informal basis (e.g. family and friends) have positive experiences including personal growth (Netto, Jenny & Philip, 2009), developing a sense of competence (Cohen, Gold, Shlman & Zuccherro, 1994) and a strengthening of the relationship between the carer and person

living with dementia (Quinn, Clare, McGuinness & Woods, 2012). As with the dementia literature, these recent developments have challenged the overriding model of dementia caregiving as highly stressful and predominantly associated with negative outcomes (Quinn, 2016).

In relation to this, the dementia caregiving experience can be understood, from a positive perspective, within an authentic partnership framework conforming to relational care theory, rather than person-centred. For example, the importance of synergistic relationships in which interdependency and reciprocity are essential have been stressed (Dupis et al., 2011). This conducive relationship refers to an equal partnership between a caregiver and a person with dementia in which both work together to make the best of their situation (Keady & Nolan, 2003). Most recently, the role of a person with dementia in this partnership has been explored with a long-term commitment and a shared history important in maintaining positive relationships (La Fontaine & Oyebode, 2014).

Relational care acknowledges that people very rarely exist in isolation and that frameworks and model for practice or care should revolve around the system a person belongs to. To create an enriched environment in which a person with dementia, their carer and healthcare professionals feel valued and supported, The Senses Framework was developed by Nolan et al., (2006). The senses consist of six domains that underpin good relational care and are applied on an older person level, a staff level and a family carer level. Briefly, these senses are:



- A sense of security
- A sense of continuity
- A sense of belonging
- A sense of purpose
- A sense of achievement
- A sense of significance.

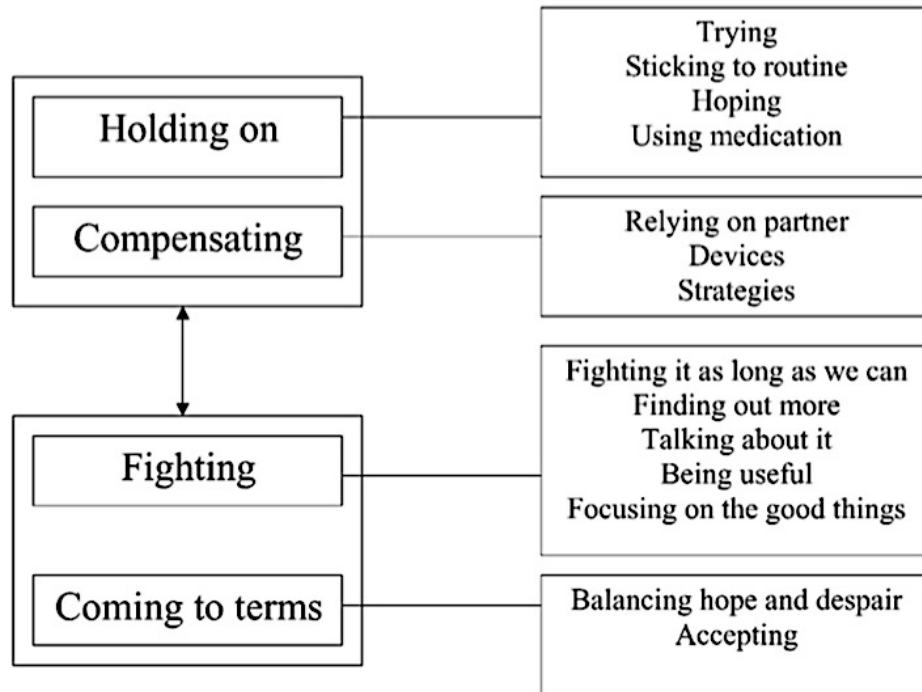
Whilst originally developed for applications within care homes, it has since been applied in a range of settings such as those for people with dementia living within the community (Ryan, Nolan, Reid & Enderby, 2008).

#### *1.3.1.2 Coping*

Qualitative research in positive psychology for individuals with dementia tends to be dominated by the construct of coping. For example, a substantial review documenting the perspective of the person with dementia concluded that coping, within this framework, consisted of strategies of integration and acceptance in order to actively compensate for impairments and strategies of denial to withdraw and protect oneself from a painful confrontation with the disease (de Boer, et al., 2007).

An interpretive phenomenological analysis has also been conducted to assess the ways in which people with Alzheimer's disease cope with its onset (Clare, 2002). Themes of holding on, compensating, fighting and coming to terms with dementia were identified but coping was operationalised as reflecting a tension between poles of maintaining an existing sense of self and integrative responses allowing for the development and adjustment of self-concept. This operationalisation, it was suggested, resulted in tension and a need to find an equilibrium. Figure 1.5 illustrates that, although aiming to increase

understanding of wellbeing and self-efficacy for people with dementia, Clare (2002) concluded with a model of coping in dementia that resides within a contextual framework of resisting threats, grief, loss and uncertainty.



*Figure 1.5 Clare (2002) model of coping in dementia*

Indeed, some researchers have called for a reappraisal as to the context in which we place the positive strategies or experiences within dementia, suggesting that these contexts are too narrow to fully appreciate the experience of dementia. Most recently, Wolverson, Clarke and Moniz-Cook (2015) called attention to the contextual basis of models and frameworks within dementia suggesting themes of uncertainty or loss as discussed above should be viewed alternatively as bravery, persistence and wisdom.

#### *1.3.1.3 Living positively, growth and transcendence*

Whilst previous conceptualisations could be accused of misconstruing positive attributes as a means of denial or reducing them down to a coping mechanism that is

employed to manage losses and deficits incurred (Macquarrie, 2005), more recent research has suggested a more detailed explanation as to the use of positive attributes in dementia. For example, a qualitative analysis of how people with dementia experience hope concluded that it was grounded in themes of ‘live in hope or die in despair’ and ‘keep living and living well’ (Wolverson, Clarke, & Moniz-Cook, 2010). Furthermore, these authors highlighted the need to delineate positive constructs such as resilience and optimism within dementia research.

A meta-synthesis of living positively with dementia highlighted retained capacities to utilise character strengths and actively seek enjoyment and pleasure (Wolverson, Clarke, & Moniz-Cook, 2015). Three higher order themes were identified within this research: Engaging with life, engaging with dementia, identity and growth. Engaging with life referred to a general satisfaction with life and in seeking pleasure and enjoyment whilst taking active steps to engage in activities. It also referred to a theme of ‘keeping going’ which required purpose and energy. Also within this theme, the importance of love and support was discussed as a source of strength for a person with dementia who strove to make and maintain connections with others. Engaging with dementia appeared to be a form of active resilience as a means of ‘making the best’ of a situation. This was discussed as a facing of facts rather than a resignation on the part of a person with dementia. The use of humour was also employed within this theme in which the value of making others laugh contributed to a positive perspective. The last theme referred to identity and growth in which people with dementia were grateful for a life well lived and strove to preserve their sense of self and identity. Growth referred to positive experiences as a result of dementia including an enhanced self-understanding, being helpful to others, the sharing of knowledge and experience. Finally, transcending

referred to a process of accepting and consciously taking a broader view of life so that dementia is contextualised and minimises the impact upon their life.

### **1.5 Measuring Positive Outcomes: Dementia and Outcome Measurement**

The recent qualitative findings provide a strong rationale for the continued use of positive concepts for people with dementia and also provide a rationale for the development of robust outcome measures with tested psychometric properties for people with dementia. This would supplement the qualitative findings and quantitatively evidence the retained capacity for positive attributes. In turn, this may aid the development and evaluation of more specific psychosocial interventions that aim to promote and maintain wellbeing for people with dementia.

Outcomes within research are usually defined as the end results of participation and classically referred to death, disease, disability, discomfort and dissatisfaction, (Lohr, 1988). However, since their wide incorporation into research and the recognition of the positive aspects of health, they tend to measure a wide range of attributes including cognition, physical ability and personality traits. Outcome measures usually undergo a rigorous development procedure and are evaluated by means of in-depth psychometric analysis (Moniz-Cook, et al., 2008). Examples of well-developed measures include those developed with the input of the target population and experts, have an adequate level of internal consistency, follow a normal distribution, are observed to be correlated with theoretically related measures and are sensitive to change (Terwee, et al., 2007).

Previously, reflecting the models of dementia already discussed, outcome measures for dementia have been developed to assess symptoms of dementia such as cognitive deficits and other neuropsychiatric symptomology including anxiety and depression.

Whilst this led to a wealth of benefits for people with dementia, measures of positive strengths and attributes appear to have been neglected. Also, previously, there appeared to sometimes be an assumption that people with dementia were unable to accurately make self-judgements and, as such, proxy raters (often carers) were sometimes used in place of ratings from people with dementia themselves. Indeed, it is only relatively recently that people with dementia themselves have been asked to provide answers on outcome measures. This may be partly attributable to an emerging awareness of variance between answers given by proxies and people with dementia observed in the 1990's (Burke, et al., 1998; Gilley, et al., 1995; Ott & Fogel, 1992) and the emergence of the person-centred care framework, in which the importance of the person coming first and retention of personhood within dementia was proposed (Kitwood, 1997).

This shift in outcome measurement for people with dementia can be illustrated by work conducted on Cognitive Stimulation Therapy (CST) trials. As the research was being developed, proxy raters were used to assess its efficacy (Spector, et al., 2003).

However, more recent trials favour ratings on measures from the participants themselves (Yates, Leung, Orgeta, Spector, & Orrell, 2015). Furthermore, a range of self-completion outcome measures have been developed for people with dementia in domains such as cognition (Folstein, Folstein, & McHugh, 1975), physical functioning (Bucks, Ashworth, Wilcock, & Siegfried, 1996) and quality of life (Logsdon, Gibbons, McCurry, & Teri, 1999).

## **1.6 Summary**

Positive psychology is not intended to replace what is known of suffering or disorder but to supplement it. Whilst previous research has contributed to a wealth of

understanding of disorders within dementia including depression and anxiety, it is now time to acknowledge that positive concepts may also have a role to play.

A lack of gold standard outcome measures mean that positive psychology is in its infancy with regard to the measurement of positive attributes for people with dementia. The qualitative literature provides a strong rationale for the development of robust outcome measures to properly investigate its role within wellbeing for people with dementia. Developing such measures specifically for people with dementia allows for these positive characteristics to be defined in the way that is most valid and suitable for this population. This definition may or may not be identical to other populations but until it is properly investigated it cannot be assumed one way or another. In order to make this a reality, people with dementia must be included at every stage of the development procedure to ensure that appropriate measures for this population are developed. A means of accomplishing this may be facilitating focus groups of people with dementia to collaboratively produce conceptualisations for positive concepts and to generate items verbatim for measures. This would ensure that developed measures have high levels of content validity for this population.

To conclude, the qualitative literature conducted to date provides a clear rationale for the development of scientifically robust outcome measures to assess the positive concepts identified as present for people with dementia. This will allow for an in-depth investigation of the role of positive psychology within dementia in a quantifiable manner. The scientific study of such concepts may lead to important advances in the field, including more targeted psychosocial interventions and less preoccupation with quality of life, depression and anxiety.

### 1.7 Overview and Aims of Thesis

The main aim of this thesis was to develop psychometrically robust outcome measures, rooted in positive psychology, for people living with dementia. Figure 1.6 provides a summary of the measure development processes. As such, this thesis documents the development and evaluation of two positive psychology outcome measures: the ‘Positive Psychology Outcome Measure’ (PPOM) and the ‘Engagement and Independence in Dementia Questionnaire’ (EID-Q) and the psychometric testing of the ‘Control, Autonomy, Self-realisation and Pleasure’ (CASP-19; Hyde, Wiggins, Higgs, & Blane, 2003) for people with dementia. The more specific aims, each corresponding to the same numbered chapter, were to:

1. Provide an overview of positive psychology theory and its relation to people living with dementia.
2. Source, examine and systematically appraise existing positive psychology measures that had been developed for or used with people with dementia.
3. Source, examine and systematically appraise existing positive psychology measures that have been developed for similar populations to that of dementia and examine the translatability of these measures for a population of people with dementia.
4. Identify and examine positive psychology concepts that hold importance for people with dementia by means of consultation, literature reviews and the use of experts in the field and to systematically appraise existing measures of these concepts.
5. Explore important positive psychology themes for people with dementia within a qualitative setting in order to generate items for outcome measures.
6. Appraise the psychometric properties, feasibility, clarity and readability of novel measures within an internal pilot (n =33).

7. Conduct a more in-depth appraisal of the psychometric properties of novel measures within a large-scale study (n =216).
8. Explore the factor structure of novel measures using best practice Structural Equation Modelling (SEM) techniques.
9. Evaluate the degree to which demographic and clinical characteristics impact upon novel measures and assess the relatedness of quality of life and depression by means of SEM.
10. Summarise results and discuss findings in the context of the literature, explore the limitations and methodological problems whilst making recommendations for future research.



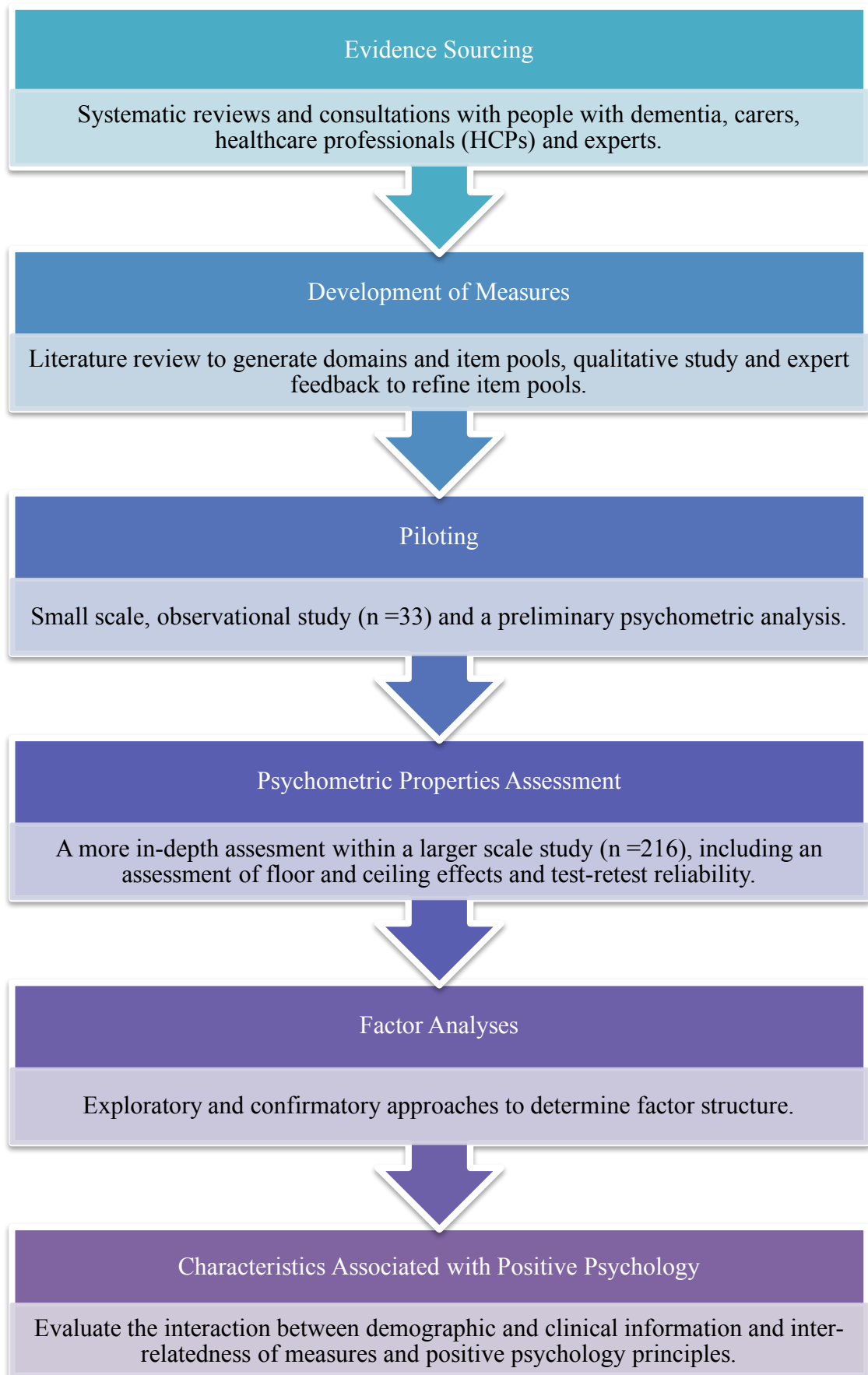


Figure 1.6 Measure development procedures

## **2. The appraisal and evaluation of positive psychology measures currently used in dementia research: A systematic review**

### **2.1 Introduction**

As discussed in Chapter 1, within the last twenty years, there have been efforts to explore dementia from a positive methodological perspective rather than a narrative of decline, centred on the medical model. Often attributed to person-centred theory (Kitwood, 1993), in which social and individual factors contributed to a unique experience of dementia for each person (Kitwood, 1997), this shifting awareness and empowerment for people with dementia is also represented through the use of outcome measurement within research.

The prevailing measurement of deficits such as depression (Alexopoulos, Abrams, Young, & Shamoian, 1988), anxiety (Shankar, Walker, Frost, & Orrell, 1999) or neuropsychiatric symptoms (Cummings, 1997) have been noted within Chapter 1, as has the preferred measurement of quality of life (Logsdon, Gibbons, McCurry, & Teri, 1999). However, more recently, measures of concepts that constitute positive psychology have been used but there is no consensus as to which are more appropriate or psychometrically robust.

### **2.2 Aims**

The aim of this chapter was to source, examine and systematically appraise existing positive psychology measures that had been developed for or used with people with dementia. Therefore, a series of sub aims were set:

1. Identify existing outcome measures in use for people with dementia.
2. Appraise the psychometric properties of existing measures.
3. Identify existing measures that require further analysis for people with dementia.
4. Make recommendations for appropriate measure usage for dementia research.

## **2.3 Methods**

### ***2.3.1 Design***

A systematic search of positive psychology outcome measures used within research for people with dementia was undertaken. Systematic principles for searching, screening and appraising studies were followed (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) and searches were then conducted to identify development information for included measures.

### ***2.3.2 Search Strategy***

PsychInfo, PubMed and MedLine were searched for results from 1998 – 2017 (Seligman, 1998). Search terms were: self-efficacy, life satisfaction, hope, resilience, wisdom, growth, coherence, control, autonomy, pleasure, self-realisation, sense of agency, gratitude, happiness, optimism, transcendence, positive, dignity, social participation, social inclusion, self-concept, reciprocity, connectedness, engagement, humour, creativity, flow, spirituality, love, compassion, benefit finding, community integration, opportunity, social adjustment, mindfulness, acceptance, successful aging, wellbeing, quality of life, independence, social health. These search terms were then combined again with: dementia, Alzheimer, cognitive impairment, senile, vascular. Truncations of search terms were used where appropriate.

Terms indicative of related fields were also included (quality of life; wellbeing; social health) and in-depth search strategy was employed in order to fully capture positive psychology measures. Titles were included if the study reported on a dementia population, abstracts were then screened for methodology indicative of the use of outcome measures and full texts were sought for the remaining results to identify positive psychology outcome measures. Ambiguous titles or abstracts were included until a decision could be made, including research with ‘dyads’ (Figure 2.1).

#### *2.3.2.1 Inclusion Criteria*

- 1) Use of a positive psychology outcome measure as identified within the search terms.
- 2) Use of above measure(s) within a dementia population.
- 3) Both development of measures and use of measures published within a peer-reviewed journal
- 4) Published between 1998- 2017.

#### *2.3.2.2 Exclusion criteria*

- 1) Studies published in a language other than English if a translation was not available.
- 2) Only used proxy-reporting.
- 3) Development information for outcome measures was not freely available.

#### *2.3.3 Appraisal of Psychometric Properties*

Included measures were grouped and a quality assessment was undertaken using established criteria (Terwee, et al., 2007) (Figure 2.2), which assesses development procedures of measures and has been used successfully in other reviews (Stoner, Orrell,

& Spector, 2015; Windle, Bennett, & Noyes, 2011). The primary researcher and an independent researcher undertook this analysis independently and a consensus meeting was held to ensure reliability of reporting (Table 2.1).

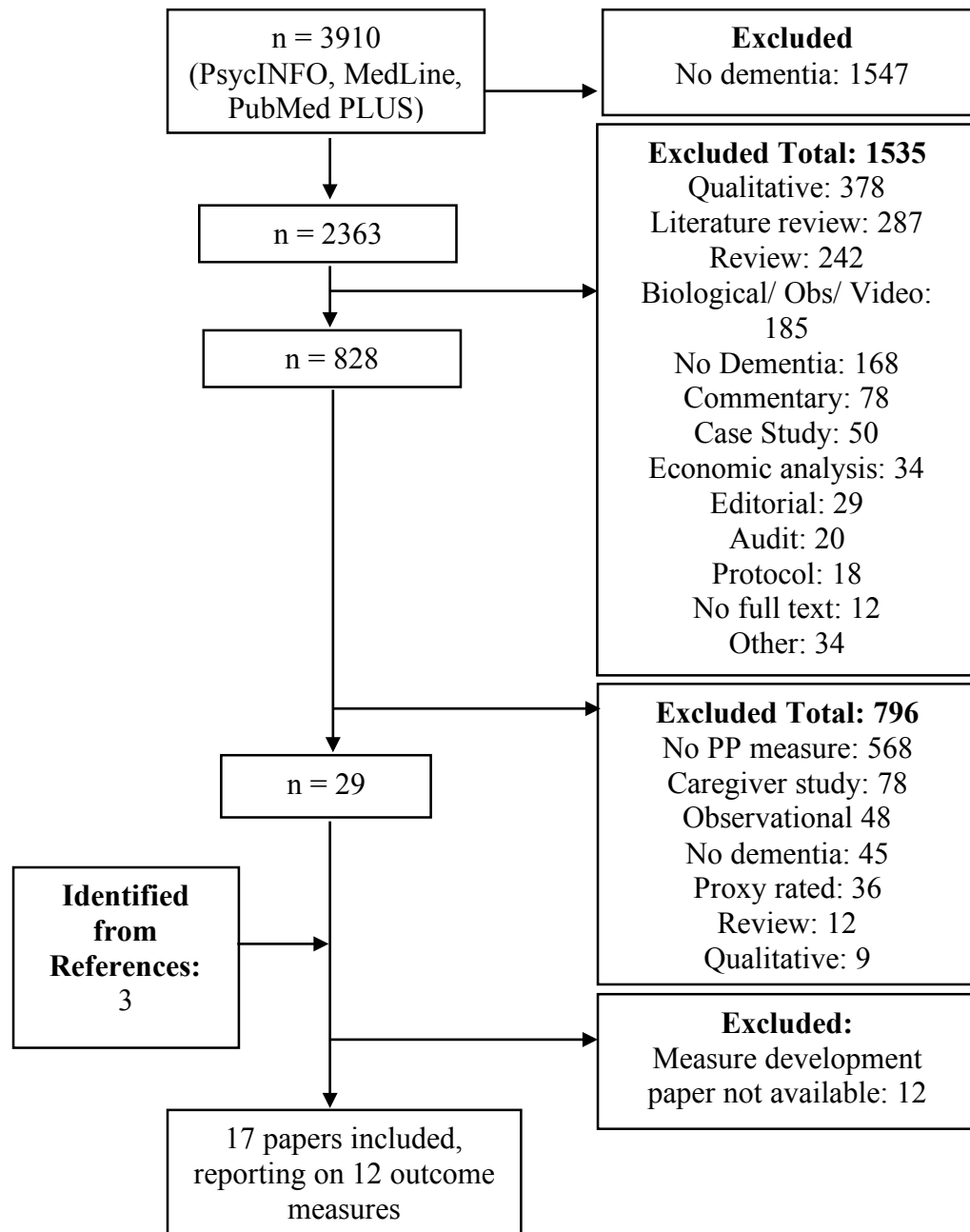


Figure 2.1 Review process for Systematic Review 1

For section of the criteria, a score of two was awarded if the study was adequately designed and appropriate statistics given, a score of one was awarded if there were methodological shortfalls such as inadequate design. If, despite adequate design, the study produced results indicating poor psychometric properties or no information was reported, a score of zero was awarded (possible range 0-18).

Property	Definition	Quality criteria
<b>1</b> Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire (the extent to which the measure represents all facets of the construct under question).	2 A clear description of measurement aim, target population, concept(s) that are being measured, and the item selection AND target population (investigators OR experts) were involved in item selection.
		1 A clear description of the above-mentioned aspects in lacking OR only target population involved OR doubtful design or method.
		0 No target population involvement OR no information found on target population involvement.
<b>2</b> Internal consistency	The extent to which items in a (sub)scale are inter-correlated, thus measuring the same construct.	2 Factor analyses performed on adequate sample size (7* #items and $\geq 100$ ) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95
		1 No factor analysis OR doubtful design or method
		0 Cronbach's alpha(s) $< 0.70$ or $> 0.95$ , despite adequate design and method OR No information found on internal consistency
<b>3</b> Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard	2 Convincing arguments that gold standard is "gold" AND correlation with gold standard $\geq 0.70$
		1 No convincing arguments that gold standard is "gold" OR doubtful design or method
		0 Correlation with gold standard $< 0.70$ , despite adequate design and method OR no information found on criterion validity
<b>4</b> Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the	2 Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses
		1 Doubtful design or method (e.g.) no hypotheses)
		0 Less than 75% of hypotheses were confirmed, despite adequate design and methods OR no information found on construct validity

		concepts that are being measured		
<b>5</b>	Reproducibility			
<b>5.1</b>	Agreement	The extent to which the scores on repeated measures are close to each other (absolute measurement error)	2	SDC < MIC OR MIC outside the LOA OR convincing arguments that agreement is acceptable
			1	Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable)
			0	MIC ≤ SDC OR MIC equals or inside LOA despite adequate design and method OR no information found on agreement
<b>5.2</b>	Reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)	2	ICC or weighted Kappa > 0.70
			1	Doubtful design or method
			0	ICC or weighted Kappa < 0.70, despite adequate design and Method OR no information found on reliability
<b>6</b>	Responsiveness	The ability of a questionnaire to detect clinically important changes over time	2	SDC or SDC < MIC OR MIC outside the LOA OR RR > 1.96 OR AUC > 0.70
			1	Doubtful design or method
			0	SDC or SDC ≥ MIC OR MIC equals or inside LOA OR RR ≤ 1.96 or AUC < 0.70, despite adequate design and methods OR no information found on responsiveness
<b>7</b>	Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	2	≤ 15% of the respondents achieved the highest or lowest possible scores
			1	Doubtful design or method
			0	> 15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods OR no information found on interpretation
<b>8</b>	Interpretability	The degree to which one can assign qualitative meaning to quantitative scores	2	Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined
			1	Doubtful design or method OR less than four subgroups OR no MIC defined
			0	No information found on interpretation

SDC - smallest detectable difference (this is the smallest within person change, above measurement error. A positive rating is given when the SDC or the limits of agreement (LOA) are smaller than the MIC).

MIC - minimal important change (this is the smallest difference in score in the domain of interest which patients perceive as beneficial and would agree to, in the absence of side effects and excessive costs).

SEM - standard error of measurement.

AUC - area under the curve.

RR - responsiveness ratio.

Figure 2.2 Terwee Criteria (Terwee et al., 2007)

Table 2.1 *Quality assessment of development procedures for systematic review 1*

<b>Construct</b>	<b>Scale</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5.1</b>	<b>5.2</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>Tot</b>
<b>Identity</b>	Self-Identity in Dementia Questionnaire	2	0	0	1	0	0	0	0	0	3
<b>Hope/ Optimism</b>	Herth Hope Index	2	0	2	1	0	2	0	2	1	10
	Adult Hope Scale	2	2	2	2	0	2	0	0	1	11
	Life Orientation Test – Revised.	2	2	0	2	0	0	0	0	0	7
<b>Religiosity/</b>	Systems of Belief Inventory	2	2	1	1	0	2	0	2	1	11
<b>Spirituality</b>	Royal free interview for religious and spiritual beliefs	1	0	1	1	0	2	0	0	1	6
<b>Life</b>	Meaning in Life Scale	2	2	0	2	0	0	0	0	0	6
<b>Valuation</b>	Terrible Delightful Scale	0	0	0	1	0	0	0	2	0	3
<b>Self-efficacy</b>	General Self-efficacy Scale	0	2	0	1	0	0	0	2	1	6
	The Self-efficacy Scale	1	2	1	2	0	0	0	0	0	6
<b>Community</b>	Brief Sense of Community Scale	1	2	0	2	0	0	0	0	0	5
<b>Wellbeing</b>	Ryff Psychological Wellbeing Scale	1	1	0	2	0	2	0	0	1	7



## 2.4 Results

After limitations were applied and duplicates removed, 3910 results were identified of which 2363 were included on title. The 1547 papers excluded at this stage did not report on a dementia population. At the second stage, 828 abstracts were included, for which full texts were sourced. Of these, the vast majority were excluded as no positive psychology outcome measures were identified (568) or measures were used in caregiver studies with no outcomes used for the person with dementia (78). Twelve studies were subsequently excluded as development information for the measures used was not published in a peer-reviewed journal or was not freely available. This left a total of 12 positive psychology outcome measures used within 17 studies for analysis (Table 2.2). Development scores were variable, with scores ranging from three to 11. The primary researcher and independent researcher agreed on most ratings, apart from the interpretability section of the Terwee criteria. Disagreements were discussed until a consensus could be reached.

### 2.4.1 Identity

The Self-identity in Dementia (SID; Cohen-Mansfeld, Golander, & Arnheim, 2000) (3/18) was the only measure identified to have been developed within a dementia population. It was notably lacking all psychometric information on the assessment criteria apart from content validity, for which it scored two points, and construct validity for which it scored one point. This was due to the involvement of the target population and experts in item development and a clear description of the aims and domains to be measured.

In a predictive analysis of variance in mood and quality of life from aspects of identity, authors suggested that a model including aspects of identity could predict depression.

More specifically, scores on the SID family and leisure subscales significantly predicted depression ( $p < .01$ ) (Caddell & Clare, 2012), lending evidence to the SID's predictive validity. An indication of discriminant validity was found between identity and cognition, as Caddell and Clare (2013a) observed no significant correlation between mean SID scores and the CERAD cognitive battery. The SID was also used in an additional study examining differences in identity of people with dementia and older adults without dementia. Both groups scored family role as the strongest aspect of their identity and occupational identity as their weakest, suggesting that dementia may not negatively affect identity, within early stages. This provides a further indication of the SID's content validity and is supported by an additional study that reported family identity as being most important (87%) (Cohen-Mansfeld, Thein, Dakheel-Ali, & Marx, 2010). Evidence of the SID's convergent validity was also observed between self-identity, engagement duration, attention and attitude ( $p < .001$ ). Healthy older adults reported significantly more distress relating to identity than people with dementia (Caddell & Clare, 2013b), possibly indicating some degree of interpretability or discriminant validity.

#### ***2.4.2 Hope***

The Herth Hope Index (HHI; Herth, 1992) and Adult Hope Scale (AHS; Snyder, et al., 1991) were two of the most robustly developed measures (10/18 and 11/18) and The Life Orientation Test- Revised (LOT-R; Scheier, Carver, & Bridges, 1994) scored less (7/18). All three measures failed to define a minimal important change to assess the responsiveness of the measure and the HHI reported an internal consistency indicative of multicollinearity ( $\alpha = .97$ ).

The HHI was used in a small scale feasibility study for dignity therapy for people with dementia (Johnston, et al., 2016). Pre and post intervention scores, as percentage changes, on the HHI were only available for four participants and were variable. The maximum increase was 6.3% and one participant had a decrease of 18.7%. This may indicate an issue with sensitivity to change as the HHI was found to be stable over a two-week period (.91) during the development stage. However, as this was a feasibility study, the sample size was small and no firm conclusions can be drawn for the sensitivity of the HHI in people with dementia.

The AHS was the most thoroughly developed measure of all the measures included here. Notably, it had high levels of construct and convergent validity with correlations being observed between a number of scales including life orientation, self-esteem, hopelessness and depression. Furthermore, discriminant validity was established between hope and self-consciousness.

The LOT-R was reported as having a good level of internal consistency ( $\alpha = .82$ ) and convergent validity was established between dispositional optimism, self-mastery, trait anxiety, neuroticism and self-esteem. Both the AHS and the LOT-R were used in a study examining biological markers of allostasis (the ability to maintain stability in a changing environment through psychological or behavioral change) as an index of psychological resilience. These biological markers were compared to baseline resources including hope (Meeks, et al., 2016). However, the authors reported no significant findings in relation to allostasis and hope.

### ***2.4.3 Religiosity/ Spirituality***

The Systems of Belief Inventory (SBI-15; Holland, et al., 1998) and the Royal Free Interview for Religious and Spiritual Beliefs (RFIRSB; King & Speck, 1995) scored 11/18 and 5/18 respectively. Internal consistency for the SBI-15 was excellent ( $\alpha = .93$ ) as was test-retest reliability ( $ICC = .95$ ) for both religious and non-religious groups. Furthermore, criterion validity was adequate, with the SBI-15 correlating with other measures of religiosity and there was a significant difference between scores for religious and non-religious participants, indicating discriminant validity. A small-scale study utilised the SBI to examine spiritual beliefs in people with early stage dementia (Katsuno, 2003) and a positive correlation was observed between spirituality and quality of life ( $p < .05$ ), indicating convergent validity between these measures.

The RFIRSB was developed with the use of experts and population involvement but the internal consistency analysis indicated an issue with the philosophical belief subscale (.60) and the overall internal consistency was not provided. However, test-retest reliability was adequate over a one-week period for both philosophical and spiritual subscales (.91 and .95 respectively). Furthermore, construct validity was established as there was a significant relationship between spirituality and the frequency of practice of religious faith ( $p < .005$ ) and people with dementia appeared to rate the strength of belief as most important (Jolley, et al., 2010), suggesting additional content validity of the measure.

### ***2.4.4 Life Valuation***

The Meaning in Life Scale (MLS; Krause, 2004) and the Terrible Delightful Scale (TDS; Michalos, 1980) scored 6/18 and 3/18 respectively. The MLS was developed in a

large sample of older adults. Whilst item selection did not involve target population or experts, the internal consistency ( $\alpha = .925$ ) and factor analysis yielded satisfactory results. No significant effects or trends of MLS were reported in a trial of advanced care planning and identity for people with dementia ( $p = .71$ ) (Hilgeman, et al., 2014), potentially indicating an issue with sensitivity or low sample size and study design.

The TDS was developed without the input of experts or the use of a target population and was not awarded points for content validity. Michalos (1998) undertook an extensive pathway analysis but did not report the internal consistency. However, it was one of the few papers to report the floor and ceiling effects of the measure. Predictive validity of the TDS was examined in an observational study examining the relationship between life satisfaction and functional impairment (St. John & Montgomery, 2010). Within this study, people with dementia or mild cognitive impairment had slightly lower overall life satisfaction than those without.

#### ***2.4.5 Self-efficacy***

The General Self-efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) and the Self-efficacy Scale (SES; Sherer et al., 1982) both scored moderately (6/18). Authors did not report on aspects of content validity of the GSE, but internal consistency was  $\alpha = .86$ . Subgroups were explored but no minimal important change was defined, limiting the measure's interpretability.

The GSE was used in an evaluation of a health promotion course for 89 people with dementia (Buettner & Fitzsimmons, 2009) but no significant differences between pre- and post-testing were reported. However, this may be an issue with intervention fidelity, as the authors reported significant findings in an earlier unpublished pilot study.

Authors of the SES reported some aspects of content validity but failed to report responsiveness, floor and ceiling effects or interpretability. The authors reported the internal consistency for both subscales ( $\alpha = .86$  and  $\alpha = .71$ ) but not the overall internal consistency. However, the measures demonstrated a high level of convergent validity with locus of control, ego strength, interpersonal competency and self-esteem.

Clements-Cortes (2013) used the SES to assess the effectiveness of a choir group for older adults, of which an unclear proportion had dementia. It is, therefore, not possible to draw conclusions about the content validity of this measure for people with dementia. Furthermore, the authors were not able to demonstrate the measure's responsiveness on either subscale following the intervention ( $p=.20$ ;  $p=.37$ ) but this may be attributable to the low sample size.

#### **2.4.6 Community**

The Brief Sense of Community Scale (BSCS; Peterson, Speer, & McMillan, 2008) scored moderately low (5/18), lacking information regarding test-retest reliability, responsiveness, skew of data and interpretability. There was no target population involvement or information regarding item selection. However, convergent validity was established between the BSCS and measures of community participation, depression and intrapersonal psychological empowerment ( $p < .01$ ).

Within a dementia setting, the measure was used to assess the efficacy of an intergenerational intervention but no significant effect was found ( $p = .168$ ) (Low, Russell, McDonald, & Kauffman, 2015). Authors reported no significant findings of other measures in the study including agitation and quality of life, possibly indicating issues with study design.

#### **2.4.7 Wellbeing**

The Ryff Psychological Wellbeing Scale (PWB) (7/18) contains six subscales that measure self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. It was found to have robust criterion validity and interpretability but lacked information on stability and responsiveness.

One study utilised the measure in its entirety (Gonzalez, Mayordomo, Torres, Sales, & Meléndez, 2015), one used the environmental mastery subscale (Wettstein, et al., 2014) and one used the purpose in life subscale (Mak, 2011). Gonzalez, Mayordomo, Torres, Sales and Meléndez (2015) examined the effect of reminiscence therapy within two retirement homes. The authors found significant improvements on all dimensions of the PWB, except for the purpose in life subscale, indicating the measure's ability to detect change. There was a significant interaction effect of time and group for self-acceptance ( $p = .002$ ), positive relations with others ( $p = .019$ ), autonomy ( $p = .001$ ) and environmental mastery ( $p = .003$ ). The second study utilised the environmental mastery subscale of the PWB in an observational study and provided further evidence for the measure's construct validity noting that higher walking distances and walking speed were significantly related to higher environmental mastery ( $r = .40$  and  $r = .45$ ,  $p < .05$ ) (Wettstein, et al., 2014). Mak (2011) utilised the purpose in life scale in a randomised trial and reported the internal consistency as  $\alpha = .73$ , lower than the original reported alpha ( $\alpha = .90$ ) but still satisfactory. A positive correlation was observed between purpose in life and goal pursuit ( $p < .001$ ), further evidencing construct validity.

Table 2.2 Description of included studies for systematic review 1

Construct	Outcome Measure	Study authors	Characteristics of participants with dementia	Methods	Results pertaining to measures
Identity	Self-Identity in Dementia Questionnaire (SID) (Cohen-Mansfeld, Golander & Arnhem, 2000)	1) Caddell & Clare (2012)	1) 50 PwD (52% female, 64% married, 22% widowed, 90% secondary education level)	1) Multiple regression analyses to determine the possibility of predicting variance in mood and quality of life (QoL) from aspects of identity.	1) Depression significantly predicted by model containing Tennessee Self-Concept scale physical and personal items subtotals and SID family and leisure subscales ( $F(4,44) = 4.66$ $p < .01$ ).
		2) Caddell & Clare (2013a)	2) 50 PwD (52% female, 64% married, 22% widowed, 90% secondary education)	2) Cross-sectional questionnaire based study to examine the profile of identity in early-stage dementia and healthy older people.	2) Within both groups, family role was reported as strongest, occupational weakest.
		3) Caddell & Clare (2013b)	3) 50 PwD (mean age: 77.8; SD 7.4, 52% female, 76% Alzheimer's disease (AD), 90% secondary education)	3) Cross-sectional study investigating relationships between identity and cognitive and functional abilities of people in early-stage dementia	3) Positivity of identity was significantly predicted by a model containing CERAD (cognitive battery) naming, constructional praxis and constructional praxis recall scores and Functional Activities Questionnaire (FAQ) total score $F(4,41) = .4557$ , $p < .01$ , $RA2 = .240$ .
		4) Cohen-Mansfeld, Thein, Dakheel-Ali, & Marx (2010)	4) 193 PwD in nursing home (mean age: 86, 78% female, 81% Caucasian, 65% widowed)	4) Examination of identity roles on engagement in tasks. Participants presented with stimulus twice, one with explanation of how stimulus should be used and once without modelling.	4) Self-identity most salient was family self-identity (87%), followed by leisure (62%). Positive relationship between self-identity and engagement duration, attention and attitude. All $p < .001$



Hope	<b>Herth Hope Index (HHI)</b> (Herth 1992)	Johnston et al., (2016)	7 PwD (mean age 78.4, 71.43% male)	Mixed methods, feasibility study with a pre and post design. Intervention was Dignity therapy.	No discussion of significant findings. One participant had difficulty completing HHI. Pre and post percentage scores available for four participants:  Participant one: -18.7%, Participant two: +6.25% Participant three: +2.08% Participant four: 0% change.
	<b>Adult Hope Scale</b> (Snyder et al., 1991)	Meeks et al., (2016)*	26 PwD (mean age 76.7; SD 10.23, 61.5% female, 88.5% white American)	Study of biological markers to capture allostasis as an index of psychological resilience, relating to other baseline resources including hope and optimism.	Non-significant z-stasis index (markers) of hope .33  Optimism and hope significantly negatively correlated ( $p < .01$ ).
	<b>Life Orientation Test – Revised (LOT-R)</b> (Scheier, Carver, & Bridges, 1994)	Meeks, et al., (2016)*	As above.	As above.	Optimism and hope (Adult Hope Scale) significantly negatively correlated ( $p < .01$ ).
Religiosity/ Spirituality	<b>Systems of Belief Inventory (SBI-15)</b> (Holland et al., 1998)	Katsuno (2003)	23 PwD (mean age 79; SD 6.2, 78% female, 78% white).	Descriptive mixed methods study. Observational, cross-sectional examining spirituality in early-stage dementia	22 completed SBI-15. Average score of 32.8, range of 11-45. Positive correlation between SBI and quality of life .44, $p < .05$ .
	<b>Royal Free Interview for Religious and Spiritual Beliefs</b> (King & Speck, 1995)	Jolley, et al., (2010)	29 PwD (89.7% female, 10.3% male, 96.6% white, mean Mini Mental State Examination (MMSE) score of 24).	Observational questionnaire study of PwD drawn from a memory clinic.	Strength of belief rated as most important. No statistical differences between carer and PwD ratings of own spiritual belief.

Life Valuation	Meaning in Life Scale (Krause, 2004)	Hilgeman, et al., (2014)	19 dyads (PwD mean age 82.8; SD 6.46, 68.4% female, 94.7% white).	Randomised to either intervention of minimal support group. Four sessions of intervention. Focus on maintaining identity through PIPAC intervention	No significant effect of intervention on meaning in life ( $p=.71$ ).
	Terrible Delightful Scale (TDS) (Michalos, 1980)	St. John & Montgomery, (2010)	58 PwD (mean age 82.9, 60.3% female).	Observational study examining overall life satisfaction with its subscales and to examine the impact of cognition on life satisfaction.	Life satisfaction broken down into two subscales: material and social. Moderate correlation between scales ( $p < .001$ ). PwD had significantly lower life satisfaction on subscales
Self-efficacy	General Self-efficacy scale (GSE) English Version (Schwarzer & Jerusalem, 1995)	1) Fankhauser, Drobetz, Morthby, Maercker, & Forstmeier, (2014) (German version)	1) 229 adults (mean age 74, 64 Mild Cognitive Impairment (MCI), 47 AD, 118 no impairment.	1) Investigated a mediation relationship of motivation (self-efficacy, decision regulation, activation regulation and motivation regulation) on the relationship between social support and depression.	1) Early AD: social support not correlated with depression ( $r = -.16$ , $p = .30$ ).  Motivational processes predicted depression significantly in regression ( $\beta = 0.39$ , $p < .001$ ).
		2) Buettner & Fitzsimmons (2009) (English Version)	2) 89 PwD (mean age experimental group 81.4, mean MMSE 25.6, 48 men, 41 women).	2) Evaluation of 12-week health promotion course for PwD.	2) Investigated impact of a health promotion course on wellbeing. No significant findings at post-test for self-efficacy
	The Self-efficacy scale (Sherer, et al., 1982)	Dawson, Powers, Krestar, Yarry, & Judge, (2013)	131 PwD (mean age 77.15; SD 9.45, mean MMSE 22.48; SD 5.84, 55.7% female, 61.8% married, 85.5% Caucasian, 26.8% college graduate).	Stress process modelling for PwD, using strains and QoL outcomes.	Self-efficacy perception emerged as a significant and unique predictor of QoL ( $\beta = .30$ , $p < .001$ )

<b>Community</b>	<b>Brief Sense of Community Scale (BSC)</b> (Peterson, Speer, & McMillan, 2008)	Low, Russell, McDonald, & Kauffman (2015)	40 older adults (mean age 91, 80% female, 80% cognitive impairment).	Randomised controlled trial of 12-week programme of 'Grandfriends'—intergenerational intervention.	No significant effects of group by time interaction ( $p = .168$ ).
<b>Wellbeing</b>	<b>Ryff Psychological Wellbeing scale (RPWB)</b>	1) (Mak, 2011)	1) 91 PwD (mean age 75.28; SD 9.23, 70 females, 51% African American, 47% European American, 2% Filipino American.	1) Randomised trial of goal-directed activity. Used Purpose in Life Subscale from RPWB	1) Alpha for purpose in life $\alpha = .73$ , lower than original study ( $\alpha = .90$ ).  Positive correlation between purpose in life and goal pursuit ( $r = .53, p < .001$ ), significant correlation between dementia severity and purpose in life ( $r = .35, p < .001$ ). Prediction analysis indicated people with higher goal pursuit were more likely to score higher on purpose in life, regardless of dementia severity.
		2) Gonzalez, Mayordomo, Torres, Sales, & Meléndez (2015)	2) 42PwD (mean age 80.24; SD 9.22; 69 women, 31 men, 59.5 widowed, 31 married, average MMSE 20; SD 2.55.	2) Quasi-experimental in two retirement homes, measure effect of reminiscence therapy. 23 experimental, 19 control	2) PWB all dimensions significant except for purpose in life. Significant increase in self-acceptance ( $p = .002$ ), positive relations with others ( $p = .019$ ), autonomy ( $p = .001$ ) and environmental mastery ( $p = .003$ ) for interaction effect of time and group
		3) Wettstein, et al., (2014)	3) 35 PwD (mean age 74.1; SD 7.1, 60% male).	3) Used Environmental Mastery Subscale of RPWB. Observational study of out of home behaviour using GPS tracking, and self-report questionnaires.	3) Higher walking distances and higher levels of walking speed were significantly related to higher environmental mastery ( $r = .40$ and $r = .45$ respectively $p < .05$ ).

## 2.5 Discussion

Twelve positive psychology outcome measures were identified within the constructs of identity, hope, religiosity/ spirituality, life valuation, self-efficacy, community and wellbeing as being used in 17 research studies of people with dementia. Only one of these measures was developed for people with dementia (SID). Most outcome measures identified scored moderately on their development procedures, with hope scales developed the most robustly and identity the least robustly.

Whilst the development information was lacking for the SID, it has been used successfully in a number of studies and suggests the measure is an appropriate tool for assessing identity for people with dementia. Despite the AHS scoring slightly higher than the HHI at the quality assessment stage, it is possible that the HHI may be more applicable as hope for people with dementia appears to be more generalised in nature (Wolverson, Clarke, & Moniz-Cook, 2010), rather than goal oriented (Snyder, et al., 1991). Therefore, the HHI may hold more content validity for this population.

Spirituality and religiousness appears to be a pervading concept, in that spirituality and religiousness hold significance in the self-concept and change, hope for the future and positive attitudes for people with dementia (Dalby, Sperlinger, & Boddington, 2011).

The SBI-15 appears to be an adequate tool to detect and measure spiritual beliefs, as development procedures were robust and some psychometric properties have been found to be satisfactory in dementia populations. Both the TDS and the MLS scored moderately for their development procedures. Whilst the TDS appeared to be more successful within a dementia population, it is recommended that both measures are in need of further psychometric examination before they are routinely used. Both self-efficacy scales and the BSCS scale failed to show sensitivity to their respective

interventions. Whilst this may be due to issues with the study design, rather than the measures, it is recommended that a more detailed examination of self-efficacy scales and community scales for people with dementia is needed.

Of the scales included Ryff's PWB appeared to be the most successful, in terms of its development procedures and the studies in which it was used. The lower alpha reported within a dementia population is still within the acceptable range and it appears to be sensitive to change. It would then appear that this scale is appropriate for people with dementia and it is recommended for use within research.

### ***2.5.1 Methodological problems and Limitations***

All measures included here failed to define a minimal important change, which is a requirement of the Terwee criteria for interpretability. This meant that it was nearly impossible to award scores for responsiveness. Reporting on reliability was mixed with only four studies reporting the test-retest reliability of measures. Additionally, obtaining the development papers of included measures was sometimes difficult and could only be accomplished by extensive searching.

Inferring sensitivity to change of measures within dementia studies included here was problematic, due mostly to study design including low sample sizes. A large majority of the studies included were feasibility studies and were not powered to detect effect sizes. Furthermore, a measure's failure to detect change may have been as a result of the intervention rather than capability of the measure. For example, an intervention designed to reduce anxiety may not show any effect on a depression measure. This limits the conclusions that can be drawn from this study.

Whilst an effort was made to include search terms that were all-encompassing and indicative of positive psychology, it is noted that definitions of what constitutes this theory vary. Consequently, broad search terms including the related fields were used resulting in a large number of studies excluded. The criteria used here were comprehensive enough to cover most aspects of a measure's psychometric properties. However, it may have been overly constraining as responsiveness and interpretability were rarely reported. Future authors may wish to include such information for the purpose of reviews or for measure selection.

### **2.5.2 Conclusion**

Twelve positive psychology outcome measures, with development information available, have been used within dementia research. However, the quality of the development procedures was variable, with authors failing to report important aspects of psychometric analyses including responsiveness and stability. The HHI, SBI-15 and PWB appear to be the most psychometrically sound and appropriate for people with dementia, but further research is needed to determine whether other concepts may be more pertinent for this population.

### **3. Review of positive psychology outcome measures for chronic illness, traumatic brain injury and older adults: Adaptability in dementia?**

(Stoner, Orrell & Spector, 2015)

#### **3.1 Introduction**

Chapter 2 illustrated that few positive psychology outcome measures for people with dementia were in existence. Of those that were, psychometric properties were variable and, consequently, there was a need to widen the search and examine positive psychology in use for other populations.

Whilst positive psychology research is only just beginning to be applied within dementia settings, a vast array of positive psychology research for other populations including young adults and workers within organisations exists (see Hefferson & Boniwell, 2011). In order to ensure that all appropriate existing measures of positive psychology were sourced, similar work in other populations was considered.

To ensure that other measures had an adequate level of content validity, prior to any validation work, similar populations to that of dementia were used within this review. Firstly, chronic illness populations were selected due to the persistent, incurable nature of chronic illness and included the cancer and arthritis literature. Secondly, Traumatic Brain Injury (TBI) populations were selected for their shared symptoms including impairment of cognitive, physical and psychosocial functions. TBI was selected, over Acquired Brain Injury (ABI) as ABI includes but is not limited to populations of hypoxia, illness, infection, substance abuse and toxic exposure. Finally, older adult

populations were selected as they share similar issues in old age and this population has the highest prevalence of dementia (Alzheimer's Society, 2014).

### **3.2 Aims**

The aim of this chapter was to source, examine, systematically appraise existing positive psychology measures that had been developed for similar populations to that of dementia and examine the translatability of these measures for a population of people with dementia. Sub-aims of this chapter were to:

1. Assess the psychometric properties of positive psychology outcome measures in use for chronic illness, Traumatic Brain Injury (TBI) and older adults.
2. Appraise the potential applicability of measures of positive outcomes for people with dementia.

### **3.3. Methods**

#### ***3.3.1 Design***

A systematic search and psychometric property appraisal of published positive psychology outcome measures for people with chronic illness, traumatic brain injury and for older adults was undertaken. Systematic principles were followed for searching, screening and appraising results (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). Constructs denoting positive psychology were sourced from current literature (Hefferson & Boniwell, 2011; Seligman, 2002; Seligman & Csikszentmihalyi, 2000) to identify salient and pertinent constructs. Such constructs included resilience, hope, optimism, autonomy and spirituality.



### ***3.3.2 Search Strategy***

The following electronic databases were searched: PsychINFO, MedLine and PubMed. Search terms were: measure, instrument, questionnaire, quiz, test and scale combined with goal, life satisfaction, self-efficacy, hope, resilience, cope, wisdom, growth, coherence, control, autonomy, pleasure, self-realisation, sense of agency, gratitude, happiness, optimism, transcendence, positive, dignity, social participation, social inclusion, self-concept, humour, creativity, flow, spirituality, love, compassion, benefit finding, community integration, opportunity, social adjustment, mindfulness, acceptance and successful aging. These search terms were then, again, combined with: chronic illness, traumatic brain injury and older adult. Truncations of search terms were used where necessary. Search terms such as ‘quality of life’ and ‘wellbeing’ were not included as the review focused on concepts that contribute to these dimensions. In the first instance, studies were screened for the development of a positive psychology outcome measure.

Studies were also screened for independent assessments of psychometric properties of a positive psychology outcome measure in either a chronic illness, TBI or an older adult population (hereafter referred to as ‘validation studies’). If a validation study was identified, a search for the original psychometric development study was performed, even if this date preceded 1998. Finally, a hand check of text and reference lists was conducted to identify additional measures.

*3.3.2.1 Inclusion Criteria*

1. Outcome measures published in a peer reviewed journal.
2. An outcome measure purporting to measure a specific construct, as identified in the search terms, within positive psychology and developed or validated in chronic illness, TBI or older adult populations.
3. Published between 1998- 2015 (1998 was when positive psychology was re-introduced by Seligman).

*3.3.2.2 Exclusion Criteria*

1. Papers published in a language other than English if a translation was not available.
2. Measures that focused on external or situational factors rather than an internal trait within positive psychology.

*3.3.3 Data Extraction*

Identified abstracts were exported to EndNote where they were screened against eligibility criteria. Full text articles were then sought for studies included. In uncertain cases, of which there were six, scales were given to the primary supervisor to screen against the eligibility criteria and were discussed until a decision on it's inclusion/exclusion was reached. The primary supervisor also reviewed the final list of measures included.

*3.3.4 Appraisal of Psychometric Properties*

Included measures were grouped within the construct they intended to measure and a quality assessment was undertaken, utilising a published criterion that appraises the development process of outcome measures (Terwee, et al., 2007). This criterion has been applied in other reviews (Windle, Bennett, & Noyes, 2011) and provides a scoring system based on reported aspects of reliability and validity during measure development

(see Chapter 2, Figure 2.2). This analysis was undertaken for measure development papers only by the primary student and corroborated by the supervisory team. For each item within the criterion, positive scores (+) were awarded when the study was adequately designed and appropriate statistics are reported. An intermediate score (?) was given if there were either methodological shortfalls including inadequate description of the design or analysis and sampling issues. A negative rating (-) was awarded if, despite adequate study design and methods, the study produced results indicating poor psychometric properties. A zero (0) was awarded if the authors failed to report the appropriate information. A positive score was awarded two points, an intermediate score one point and both negative ratings and zero ratings were awarded a score of zero. These scores were then added together to produce an overall quality score for the development process of the scale with a possible score range of 0-18.

The appraisal of validation papers was undertaken to assess the degree of translatability to other populations and therefore guide selection of a measure that could be used for people with dementia. An analysis of reported psychometric properties including internal consistency (employing magnitude guidelines) (George & Mallery, 2003) and convergent validity was undertaken. A measure was identified as potentially applicable to people with dementia if reported psychometric properties within a validation study were robust and consistent with the original scale. This would indicate the measure's stability across populations.

### 3.4 Results

6709 results were identified from the databases PsycINFO, MedLine and PubMed, of which 111 potential scale and 32 validation papers were identified. Figure 3.2 summarises the steps taken during the review when including or excluding potential scales. Of the 111 potential scales, only 16 met the criteria for inclusion within this review. The main reason for the exclusion was that scales did not measure a trait or characteristic indicative of positive psychology (64 out of 109 excluded on this basis). Of the 32 validation papers, eight met the inclusion criteria. The majority of validation papers (19 out of 32) were excluded on the basis that the original scale did not meet the inclusion criteria.

The appraisal of the scale development process is contained within Table 3.1 (see figure 2.2 for original criteria). Scores were relatively low, ranging from 2-9 out of a possible 18. Overall, the Control, Autonomy, Self-Realisation and Pleasure (CASP-19; Hyde, Wiggins, Higgs, & Blane, 2003) was awarded the highest score, demonstrating its comprehensive reliability and validity for older adults. Study characteristics such including sample size and psychometric properties were synthesised to compare properties of a measure when used in a different population (Table 3.4). Table 3.4 provides a description of the 15 included measures and validations in populations of interest. In one instance, a short form version of a scale was utilised and both versions were included in the quality assessment.

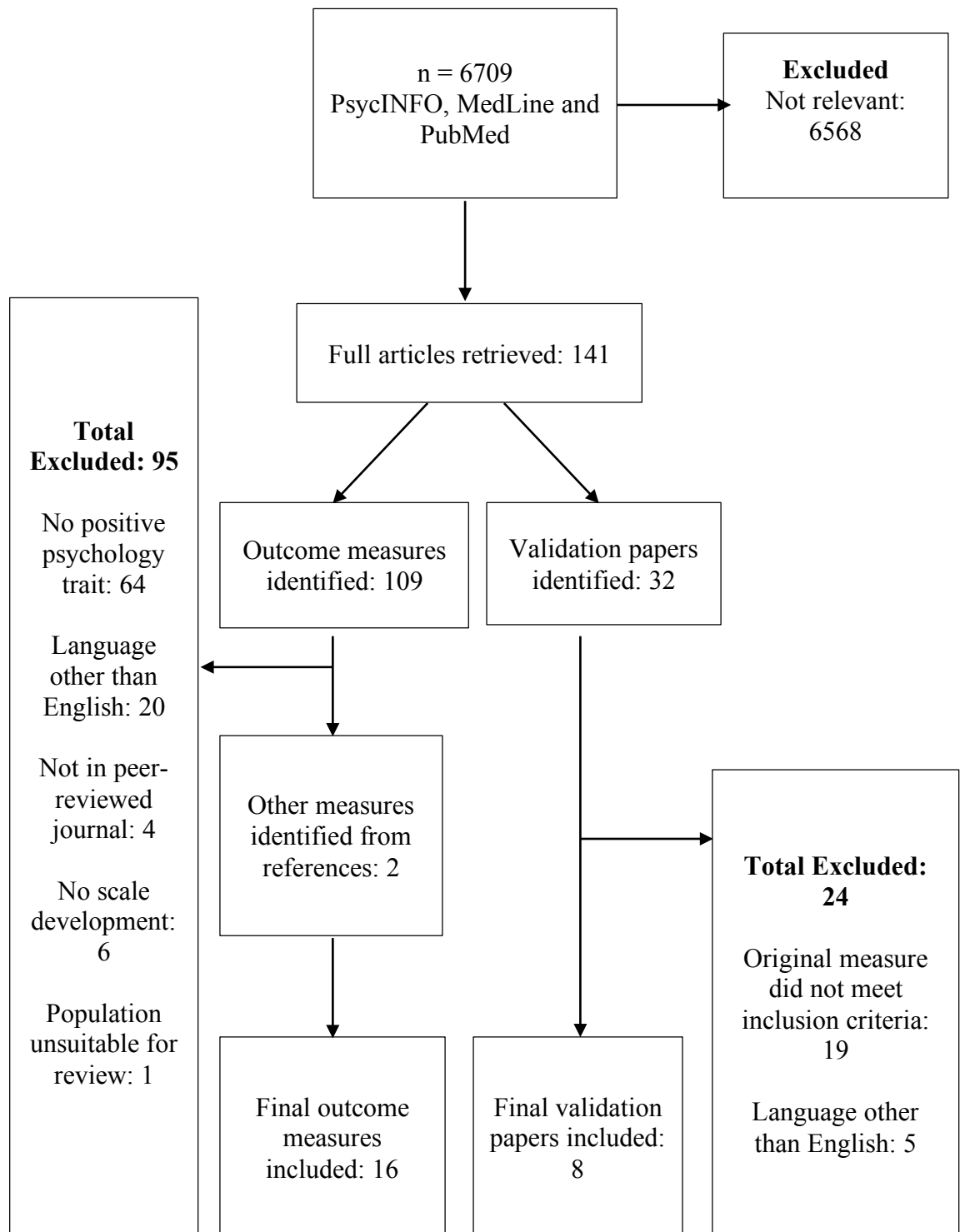


Figure 3.1 Review process for systematic review 2

Table 3.1 *Quality assessment of development procedures for systematic review 2*

Construct	Scale	1	2	3	4	5.1	5.2	6	7	8	Tot
<b>Self-efficacy</b>	Care-Receiver Self-Efficacy Scale	+	+	?	+	0	0	0	0	0	7
		2	2	1	2	0	0	0	0	0	
<b>Resilience</b>	Connor-Davidson Resilience Scale	?	?	0	?	0	?	?	0	?	7
		1	1	0	1	0	1	1	0	1	
	Brief Resilient Coping Scale	-	-	0	+	0	-	0	0	0	2
		0	0	0	2	0	0	0	0	0	
	The Resilience Scale	+	+	0	+	0	0	0	0	?	7
		2	2	0	2	0	0	0	0	1	
<b>Spirituality</b>	The Brief Resilience Scale	?	+	-	?	0	?	0	0	+	6
		1	2	0	1	0	1	0	0	1	
	Daily Spiritual Experience Scale	?	+	0	?	0	0	0	0	+	6
		1	2	0	1	0	0	0	0	2	
	Spirituality index of wellbeing	?	+	0	?	0	0	0	0	0	4
		1	2	0	1	0	0	0	0	0	
<b>Life Valuation</b>	Geriatric Spiritual Wellbeing Scale	+	+	0	+	0	?	0	0	0	7
		2	2	0	2	0	1	0	0	0	
	FACIT- Spiritual Wellbeing Scale	?	+	0	+	0	0	0	0	+	7
		1	2	0	2	0	0	0	0	2	
	The Satisfaction with Life Scale	-	-	0	?	0	+	0	0	0	3
		0	0	0	1	0	2	0	0	0	
<b>Autonomy</b>	Valuation of Life Scale	-	+	0	?	0	0	0	0	+	5
		0	2	0	1	0	0	0	0	2	
	Attitude to Aging Scale	?	+	0	?	0	0	0	+	0	6
		1	2	0	1	0	0	0	2	0	
	Maastricht Personal Autonomy Questionnaire	+	-	0	+	?	+	-	0	?	8
		2	0	0	2	1	2	0	0	1	
<b>Sense of Coherence</b>	Sense of Coherence Scale 29item and 13item	-/ -	?/ ?	0	?/ ?	0/ 0	-/ -	0/ 0	0/ 0	0/ 0	2/ 2
		0/ 0	1/ 1	0	1/ 1	0/ 0	0/ 0	0/ 0	0/ 0	0/ 0	
<b>Resourcefulness</b>	Resourcefulness Scale for Older Adults	?	+	?	?	0	0	0	0	0	5
		1	2	1	1	0	0	0	0	0	
<b>Combined</b>	Control, Autonomy and Self-Realisation and Pleasure-19	+	+	?	+	0	0	0	+	0	9
		2	2	1	2	0	0	0	2	0	

### **3.4.1 Resilience**

Four scales measuring resilience were identified: The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003), the Brief Resilient Coping Scale (BRCS; Sinclair & Wallston, 2004), the Resilience Scale (RS; Wagnild & Young, 1993) and the Brief Resilience Scale (BRS; Smith, et al., 2008). The CD-RISC and RS were awarded the highest scores for resilience measurement (7/18), whilst the BRS scored six and the BRCS scored two. In particular, the RS was rigorously developed with items being generated following an extensive literature review and in-depth interviews with the target population contributing to its high score on the content validity criterion.

Internal consistency using Cronbach's Alpha was reported in all four development studies. Scores ranged from acceptable to good, of which the BRS had the highest score. Test-retest reliability was reported for three of the four (CD-RISC, BRCS and BRS) and scores again ranged from acceptable to good, of which the CD-RISC was the highest. Convergent validity was reported for all four scales with expected and significant results, of which the CD-RISC was the most thorough. Overall correlations between the BRCS and scales attempting to establish convergent validity were not established. However, expected and significant correlations were reported for subscales. The BRS was found to be positively correlated with a number of scales and subscales including the CD-RISC. The RS was found to be positively correlated with life satisfaction and morale and negatively correlated with depression. Sensitivity to change was established for two scales (CD-RISC and BRCS), with the CD-RISC showing a significant effect of time and an interaction effect between time and response category, indicating an increase in score associated with overall clinical improvement. The BRCS demonstrated a significant linear effect across four assessment periods and an increase in the mean average score pre- and post-intervention (Table 3.2). Predictive validity

was reported for two scales (BRCS and BRS). For the BRCS, the authors created an Outcomes Index, consisting of six standardised variables reflecting post-intervention scores. This outcomes index had an adequate alpha reliability score ( $\alpha = 0.86$ ) and was found to be a moderately significant predictor of post-intervention outcomes ( $p < .03$ ). The BRS predicted outcomes for perceived stress, anxiety, depression, positive affect and physical symptoms.

Two validation papers were identified within this review. The CD-RISC was validated in a Native American, older adults sample and was found to have excellent internal consistency ( $\alpha = .93$ ) (Goins, Gregg, & Fiske, 2012). Its convergent validity was also established by significant positive correlations scales of self-efficacy and mastery and negatively correlated with depression and handgrip strength. The RS was translated and validated in a Spanish chronic musculoskeletal pain sample and was found to have adequate psychometric properties (Ruiz-Párraga, López-Martínez, & Gómez-Pérez, 2012). The authors also analysed the scale's stability and found no significant differences across two time points. The RS was also found to be positively correlated with pain scales and negatively correlated pain catastrophising. Overall, the CD-RISC appears to be the most psychometrically robust measure, reflected in the quality assessment and validation stages. Although the RS scored equally as well as the CD-RISC, the latter was subject to an increased level of validity checks including sensitivity to change analyses and stringent validity checks and, therefore, the CD-RISC seems the most appropriate scale for further validation in a dementia population.

### ***3.4.2 Self-efficacy***

The Care-Receiver Efficacy Scale (CRES; Cox, Green, Seo, Inaba, & Quillen, 2006) was the only measure of self-efficacy to meet the inclusion criteria for this review. It



was given a moderate 7/18 for the scale development, notably lacking information regarding reproducibility, responsiveness and interpretability. The CRES had an adequate reported internal consistency for most of its subscales, however, one of these came close to the minimum required score of  $\alpha = 0.70$ . The authors conceded that this subscale was of questionable practical use but was retained for potential future analysis and modification. The authors reported expected negative correlations between depression and subscale four (performance related quality of life) but, overall, subscale correlations with validation measures were only moderate ranging from  $r = 0.3- 0.4$ . No validation studies for the Care-Receiver Efficacy Scale were identified within this review. The CRES, although scoring moderately on the quality assessment, appears to be of questionable practical value and would benefit from further development and analysis.

### ***3.4.3 Religiousness/ Spirituality***

The Daily Spiritual Experience Scale (DSES; Underwood & Teresi, 2002), the Spirituality Index of Wellbeing (SIWB; Daaleman, Frey, Wallace, & Studenski, 2002), the Geriatric Spiritual Wellbeing Scale (GSWS; Dunn, 2008) and the Functional Assessment of Chronic Illness Therapy- Spiritual Wellbeing Scale (FACIT-Sp; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002) were identified for inclusion within this review, of which the final two were given the highest rating during the quality assessment stage (7/18).

Internal Consistency was reported for all four scales and ranged from good to excellent, of which the DSES scored highest. However, two items were found to be collinear ( $\alpha = 0.96$ ) for this scale, as participants seemed unable to distinguish between finding comfort and finding strength at an item level. The authors conceded that if similar

patterns were to be found in other populations, one of the items should be omitted.

These items were nevertheless included within the final scale. Test-retest reliability was only reported for the GSWS with a significant relationship being found ( $p < .001$ ).

Convergent validity was reported for all scales with acceptable, expected correlations for each (Table 3.2). Of particular note was the DSES, for which the authors reported positive correlations for a range of factors including optimism, social support and quality of life and negative correlations with anxiety and alcohol consumption.

Furthermore, the DSES was reported to have good construct validity.

Validations in appropriate populations were identified for the DSES and the SIWB. The DSES has been translated and validated for French older adults and was found to have excellent internal consistency, test-retest reliability and convergent validity, highlighting its possible applicability for older adults with dementia (Bailly & Roussiau, 2010). The SIWB was validated in a chronic illness setting and was also found to have excellent internal consistency, test-retest reliability and convergent validity (Daaleman & Frey, 2004).

Overall, of the four scales identified, the GSWS and FACIT-Sp were more rigorously developed, as reflected in their higher scoring on the quality criteria (Table 3.2). Also, the GSWS and the SIWB were developed for older adults, and in the case of the SIWB, has been validated in a chronic illness population and therefore, might be more applicable in a dementia setting.

#### ***3.4.4 Life valuation***

The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985), the Valuation of Life Scale (VLS; Lawton, et al., 2001) and the Attitude towards Aging

Scale (AtA; von Humboldt, Leal, Pimenta, & Maroco, 2014) were identified and grouped under the construct of 'life valuation'. The SWLS received a score of 3/18, lacking information with regard to content validity and criterion validity, responsiveness and floor/ ceiling effects. The VLS was awarded 5/18 and lacked information as to content validity, criterion validity and responsiveness. The AtA received the highest rating on the quality assessment in the development stage (6/18) illustrating the thoroughness of the reporting style for the AtA, which received a positive score for its reporting of floor/ ceiling effects, a criterion that appears to be underreported in scale development.

All reported good internal consistency and suitable convergent assessments (Table 3.2). The VLS consists of two subscales (positive valuation and negative valuation) and appeared most thorough in the assessment of convergent validity. Authors noted a significant, positive relationship between wellbeing, hardiness and mastery and positive valuation of life and a significant negative relationship between negative valuation of life and wellbeing, hardiness and mastery. Furthermore, a negative relationship was found between positive valuation of life and depression. In contrast, the AtA reported aspects of construct validity but only weak negative correlations with other scales as a questionable indicator of discriminant validity.

Three validation studies were identified for the SWLS, consisting of a translation and validation in Turkish older adults (Durak, Senol-Durak, & Gencoz, 2010), a translation and factor analysis in Spanish adolescents and older adults (Pons, Atienza, Balaguer, & Garcia-Merita, 2000) and a Portuguese translation and validation for older adults (Sancho, Galiana, Guiterrez, Francisco, & Tomas, 2014). Two of these studies reported good to excellent internal consistency for older adults, with appropriate sample sizes

and expected significant relationships. The Spanish translation examined factorial variance between adolescents and older adults and concluded that the SWLS was indeed sensitive to both these age groups, with an acceptable one-factor model identified for both. No validation studies were identified for the VLS or AtA.

Overall, it appears that the SWLS scale seems most appropriate for future use for people with dementia. Although its development was not as rigorous as the VLS, it has been the subject of at least three validation studies for older adults, illustrating its applicability to older adults cross culturally. The AtA is a new scale, which would benefit from additional development with regard to convergent validity before adaption for people with dementia.

#### ***3.4.5 Autonomy***

The Maastricht Personal Autonomy Questionnaire (MPAQ; Mars, et al., 2014) received a score of 8/18 for the quality assessment, illustrating adequate development, particularly with regard to establishing content validity. Acceptable reproducibility was reported using Intraclass Correlation Coefficient (ICC) for each of the three subscales and a wide range of expected correlations were noted, thereby establishing its convergent validity (Table 3.2). No validation studies were identified for the MPAQ but this is unsurprising as the scale was published in 2014.

#### ***3.4.6 Sense of Coherence***

The Sense of Coherence Scale (SOCs; Antonovsky, 1993) is a 29 or 13-item measure. Both the 29 and 13-item scale were given a low score of 2/18 for development processes, largely because information was not available for most of the criteria. For example, whilst it is noted that the scale was developed with a Jewish population, there

was no indication of norms for this sample. Furthermore, content validity was difficult to establish, as there was no record of target population involvement in the generation of items and, as there was no examination of convergent/ divergent validity, construct validity for the scale was questionable.

Internal consistency for both the 29 and 13-item scale was reported and found to be high. However, convergent validity was not examined as the scale was proposed as ‘novel’ and face validity was established from colleague feedback to the author. The 13-item SOCS was subject to a confirmatory factor analysis in a Dutch sample of young adults living with a chronic illness ( $n = 2781$ ) (Luyckx, et al., 2012). Results indicated that two items should be dropped to improve overall consistency and furthermore, the three subscales loaded onto a single order factor model with factor loadings ranging from 0.58 to 1.00.

Whilst the development of the scale was lacking in some basic areas, it has since been subject to extensive psychometric assessments. In a review of 124 studies (Eriksson & Lindström, 2005), the SOCS was reported to have adequate internal consistency, to be relatively stable over time and predictive of health outcomes including risk of post-traumatic stress symptoms. As such, the SOCS is a well-established outcome measure that could be adopted within psychosocial dementia research.

### ***3.4.7 Resourcefulness***

The Resourcefulness Scale for Older Adults (RSOA; Zauszniewski, Lai, & Tithiphontumrong, 2006) is a 28-item scale developed for older adults, of which there was an average of three chronic health conditions per participant. It was awarded 5/18 on the development of the scale, and notably the authors conducted in-depth factor

analyses and reported appropriate levels of internal consistency for subscales and overall scales. However, convergent validity was not established for this scale and, therefore, further development is needed before the possibility of adaptation for people with dementia.

#### **3.4.8 Combined measures**

The Control, Autonomy, Self-realisation and Pleasure (CASP-19) is a 19-item scale developed in a sample of older adults with an age range of 65-75 and had the greatest score at the quality assessment stage, achieving a score of 9/18. This illustrates its thorough psychometric development, including the use of experts, discussion groups with target populations and factor analyses. Internal consistency was reported for each of the 4 subscales and ranged from  $\alpha = 0.59$  to  $\alpha = 0.77$ . Whilst this falls below the acceptable limit for Cronbach Alpha, the authors compensated for this by undertaking a factor analysis which suggested evidence for a single, underlying quality of life factor, with strong factor loadings occurring for each of the subscales (0.71 to 0.88) on a latent factor. The scale was also strongly positively correlated with the Life Satisfaction Index-W ( $p = .001$ ).

Whilst The CASP-19 is used as an indicator of quality of life, it was developed using a needs satisfaction model, strongly linked with Maslow's work on human motivation (Maslow, 1968) and assesses quality of life by the degree to which the requirements of the four domains it consists of are satisfied. However, as the CASP-19 is used as a quality of life indicator, validation studies were unlikely to be identified within this review. Nevertheless, the CASP-19 appears to be a psychometrically sound measure that could be used for people with dementia in future instances.

Table 3.2 Description of included studies for systematic review 2

Construct	Instrument	Description	Sample developed in	Reliability	Validity	Translatability identified within review.
Resilience	Connor-Davidson Resilience Scale (Connor & Davidson, 2003)	25 item scale, 5 point Likert scale (0-4) with responses ranging from “0- not true at all” to “4- nearly all the time”. Higher scores reflect greater resilience.	American sample (n = 806; mean age 43.8). Random-digit dial general population (non help-seeking), primary care recipients, psychiatric outpatients, GAD and PTSD.	<u>Internal Consistency:</u> Cronbach Alpha 0.89 (Good)  <u>Test-retest:</u> intraclass correlation coefficient of 0.87 (Good)	<u>Criterion:</u> Positive correlation with Kobasa hardiness ( $r=0.83, p<.0001$ ) <u>Convergent:</u> SSS ( $r=.36, p<.0001$ ). Negative correlation with PSS-10 ( $r=-.76, p<.001$ ), SVS ( $r=-.32, p<.0001$ ) and SDS ( $r=-.62, p<.0001$ )  <u>Sensitivity to change:</u> effect of time and interaction between time and response category ( $F(1,46)=17.36, p<.0001$ and $F(1,47)=12.87, p<.001$ respectively). Indicates scores increased with overall clinical improvement.	<u>Validation study in in Older Adults (age range 55-75+)</u> (Goins, Gregg, & Fiske, 2012): Excellent internal consistency ( $\alpha=.93$ ).  <u>Convergent:</u> Established (CES-D, GSES, PSMS and MOS-SSS: $p<.001$ ; Handgrip strength: $p<.050$ )
	The Brief Resilient Coping Scale (Sinclair & Wallston, 2004)	4 item, 5 point Likert Scale with responses ranging from “1- does not describe you at all” to “5- describes you very well”.	American Sample with Rheumatoid Arthritis (Sample 1 n = 90; mean age 46, Sample 2 n = 140; mean age 57.8)	<u>Internal Consistency:</u> Cronbach Alpha 0.69 (Acceptable)  <u>Test-retest:</u> correlation = .71 (5-6 week baseline) and .68 (3 month follow up)	<u>Convergent:</u> Expected correlations with measures of personal coping resources, pain coping behaviours and psychological wellbeing (overall scales not reported).  <u>Predictive:</u> Significant predictor of post-intervention outcomes as measured by Outcomes Index ( $b=2.35; p<.03$ )  <u>Sensitivity to change:</u> significant linear effect across four assessment periods ( $F(1,81)=7.78, p<.01$ ) and paired t tests showed increase in mean average score pre and post intervention ( $t(89)=2.12, p<.05$ ).	

	<p>The Resilience Scale (Wagnild &amp; Young, 1993)</p>	<p>25 item scale, 7 point Likert scale. Responses ranging from “1- Disagree” to “7-Agree” with higher scores reflecting greater resilience.</p>	<p>Developed in a qualitative study of 24 women using verbatim statements to generate items. Piloted with 39 undergraduate nursing students.</p> <p>Psychometric properties explored in general population (n =810)</p>	<p><u>Internal consistency:</u> At pilot <math>\alpha = .89</math> (Good). In subsequent studies correlations ranged from <math>\alpha = .67</math> (Acceptable) to <math>\alpha = .84</math> (Good) (<math>p &lt; .01</math>).</p>	<p><u>Convergent:</u> Positive correlation with Life Satisfaction Index-A (<math>r = 0.30</math>), and Morale (PGCMS) (<math>r = 0.28</math>). Negatively correlated with depression (<math>r = -0.37</math>). All significant to <math>p &lt; .001</math>.</p>	<p><u>Spanish translation of RS in chronic musculoskeletal pain sample (Ruiz-Párraga, López-Martínez, &amp; Gómez-Pérez, 2012) (n = 300).</u></p> <p><u>Internal consistency:</u> <math>\alpha = .92</math> (Excellent).</p> <p><u>Test-retest reliability:</u> <math>r = .90</math>; <math>P &lt; .001</math>.</p> <p><u>Scale stability:</u> no significant difference over two time points (<math>t(299) = 95.297</math>; <math>p = .15</math>).</p> <p><u>Construct:</u> significantly correlated with pain scales e.g. Pain Catastrophizing Scale (<math>-.70</math>), Spanish version of the Chronic Pain Acceptance Questionnaire (.74)</p>
	<p>The Brief Resilience Scale (Smith, et al., 2008)</p>	<p>6 item, 5 point Likert scale. Three items negatively coded. Responses ranging from “1- strongly disagree” to “5- strongly agree”. Also includes “3- neutral”.</p>	<p>American population (n =354) including undergraduate students, cardiac rehabilitation and fibromyalgia patients.</p>	<p><u>Internal consistency:</u> <math>\alpha = .80</math> to <math>\alpha = .91</math> (Good)</p> <p><u>Test-Retest (ICC) = .62- .69</u> from specific subset of participants within sample.</p>	<p><u>Criterion/ Convergent:</u> Positively correlated with the resilience measures, social support, optimism and purpose in life (statistics of overall scales not included). Negatively correlated with behavioural disengagement, denial, and self-blame (statistics of overall scales not included).</p> <p><u>Predictive:</u> Predicts expected outcomes for perceived stress, anxiety, depression, negative affect, positive affect and physical symptoms (<math>p &lt; .01</math>).</p>	



Self-Efficacy	Care-Receiver Efficacy Scale (Cox, Green, Seo, Inaba, & Quillen, 2006)	5 point Likert scale including a neutral midpoint.	American functionally disabled older adults (n =177; mean age= 78.42;	<p><u>Internal Consistency:</u> subscales ranged from <math>\alpha = .69</math> (fair) to <math>\alpha = .91</math> (excellent).</p> <p>Authors noted that Subscales 3 (perception of dependence) and 5 (accepting help) were of questionable practical used but were retained for potential future modification.</p>	<p><u>Convergent:</u> Moderate correlations with validation measures (.3-.4) and subscales at a low to moderate level. Subscale 5 did not overlap other subscales to any marked extent. Subscale 4 (performance related QoL) negatively correlated with depression (<math>r = -.47</math>).</p> <p><u>Face Validity/ Content Validity:</u> item difficulty and item location rating from four 'experts'. Spearman's rho used to correlate empirical item location and mean judged item location by subscale. Correlations for subscales 4 (performance related QoL) and 5 (accepting help) (<math>p = .020</math>). Expert rating of Subscales 1 and 2 unrelated to empirical item locations.</p>	
Religiousness/ Spirituality	The Daily Spiritual Experience Scale (Underwood & Teresi, 2002)	16 item/ 6 item, 6 point Likert scale. Usually self-administered. Responses range from "1- many times a day" to "6- never or almost never". 16 <sup>th</sup> item responses "not close at all" to "as close as	Study of Women Across the Nation (SWAN) (n =233; 100% women; mean age= 46.76). Patients with arthritic pain (n =45). University of Chicago area (n =122). GSS (1997-1998) used 6item scale (n =1445; mean age 45.64).	<p><u>Internal Consistency:</u> item correlation in SWAN study range from .60-.80 (acceptable) 2 items collinear: "finds strength in religion, spirituality" and "finds comfort in religion, spirituality" (<math>\alpha = .96</math>)</p>	<p><u>Construct:</u> SWAN study lower scores in African American women, indicating greater degree of DSE (<math>p &lt; .01</math>). Pattern repeated in GSS sample (6 item scale; <math>p &lt; .01</math>). Non-religious people had significantly higher scores in GSS sample than Catholic and Protestants (<math>p &lt; .01</math>).</p> <p><u>Convergent:</u> SWAN study- frequency of DSE negatively correlated with psychosocial factors including anxiety, alcohol consumption, and positively correlated with optimism, social support and QoL (all significant to <math>p &lt; .01</math>).</p>	<p><u>Translation and Validation in French Older Adults (Short Form) (Bailly &amp; Roussiau, 2010):</u> (n = 338; mean age 77.87; women 62.6%; men 37.4%)</p> <p><u>Internal Consistency:</u> <math>\alpha = .92</math> (excellent). Mean item correlation <math>\alpha = .65</math>.</p> <p><u>Test-Retest:</u> subsample of 40 participants after two weeks showed good temporal stability (<math>r = .85</math>).</p> <p><u>Convergent:</u> positively correlated with SWLS (.22, <math>p &lt; .01</math>) and physical health (.16, <math>p &lt; .05</math> and .15, <math>p &lt; .05</math>).</p>

		possible” (4point Likert)		Cronbach alpha: $\alpha = .94-.95$ (excellent).  <u>Reliability coefficients (inter-rater):</u> .64-.78 (acceptable).	Chicago study- More frequent DSE associated with positive affect ( $r = .29, p < .01$ )	
	Spirituality Index of Wellbeing (Daaleman, Frey, Wallace, & Studenski, 2002)	12 item, 5 point Likert scale. 2 subscales. Responses range from “1- Strongly Agree” to “5- Strongly Disagree”.	Community dwelling older adults (n = 277; mean age 74)	<u>Internal Consistency:</u> $\alpha$ =.87 (good).	<u>Convergent:</u> Positive correlations with self-report health status, functional quality of life and physical functions (no statistics given). Negative correlation with fear of death and depression.	<u>American adult outpatients at primary care clinics (chronic illness) (Daaleman &amp; Frey, 2004) (n = 509; mean age 46.8).</u>  <u>Internal Consistency:</u> $\alpha = .91$ (excellent)  <u>Test Retest:</u> Subsample (n =93) tested again over telephone within two weeks (.79)  <u>Factor Analysis:</u> 56% variance accounted for by 2-factor model.  <u>Convergent:</u> positive correlation with Spiritual wellbeing scale (.62) and general wellbeing (.64). Negative correlation with depression (-.42) all significant to $p < .001$
	Geriatric Spiritual Wellbeing Scale (Dunn, 2008)	16 item scale, 6 point Likert scale. Responses range from “1- strongly disagree” to “6- strongly agree”.	Convenience sample of American community dwelling older adults (n = 138; mean age 74.2).	<u>Internal Consistency:</u> $\alpha$ = 0.76 <u>Test-Retest:</u> significant relationship ( $r$ =.60, $p < .01$ ).	<u>Convergent:</u> negatively correlated with depression (GDS) ( $r = -.32, p < .01$ )	

	Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing Scale (FACIT-Sp; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002)	12 item, 5 point Likert scale. Responses range from “0- Not at all” to “4- very much”.	American cancer patients (n =1617; median age 54.6) (chronic illness).	<u>Internal Consistency:</u> $\alpha$ =.87 (good).	<u>Convergent:</u> positively correlated with QoL (FACT-G) (.58; $p$ <.001). Negatively correlated with depression (POMS subscale) (-.48; $p$ =.0001).  <u>Content:</u> Assessed in second sample (n =131; European American 87%; cancer patients 65.7%). Moderately correlated with other religiousness scales ( $p$ <.005).	
Life Valuation	The Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985)	5 item scale, 7 point Likert scale. Responses range from “1- strongly disagree” to “7- strongly agree”. Includes a neutral midpoint “4- neither agree nor disagree”.	American undergraduate students at University of Illinois (Sample 1 n = 176, Sample 2 n = 176).	<u>Internal Consistency:</u> coefficient alpha: 0.87  <u>Test-Retest:</u> Sample 1 two-month retest coefficient =.87.	<u>Factor Loadings:</u> Single factor accounting for 66% variance (Sample 1).  <u>Convergent:</u> Positively correlated with Positive Affect (PANAS) .50 and .51 for Samples 1 & 2 respectively. Negatively correlated with Negative Affect (PANAS) -.37 and -.32 for samples 1 & 2 respectively.	<u>Validation in Turkish Older Adults (Durak, Senol-Durak, &amp; Gencoz, 2010):</u> (n = 123)  <u>Internal Consistency:</u> $\alpha$ =.81 (good).  <u>Convergent:</u> positively correlated with self-esteem ( $r$ =.20, $p$ =.023) perceived current health status ( $r$ = .20, $p$ =.027) and negatively correlated with depression ( $r$ = -.39, $p$ =.000)  <u>Spanish Translation and Analysis (Pons, Atienza, Balaguer, &amp; García-Merita, 2000):</u> Analysis of factorial variance between adolescents (n = 133) and older adults (n = 133). Acceptable one factor model for both adolescents and older adults found. Sensitive to these age groups.

						<p><u>Portuguese translation and validation in older adults (Sancho, Galiana, Guiterrez, Francisco, &amp; Tomas, 2014) (n = 1003)</u></p> <p><u>Internal Consistency:</u> <math>\alpha = .92</math> (excellent).</p> <p><u>Convergent:</u> positively correlated with perceived health (<math>.326, p &lt; .01</math>), generativity (<math>.202, p &lt; .01</math>).</p>
	Valuation of Life Scale (Lawton, et al., 2001)	19 item. Subscales of positive valuation of life and negative valuation of life.	<p>American older adults Sample 1: n = 602; mean age 77.34;</p> <p>Sample 2: n = 462; mean age 76.89;</p> <p>Sample 3: n = 138; mean age 80.64;</p> <p>Sample 4: n = 850; mean age 75.65;</p>	<p><u>Internal Consistency:</u> Positive VOL <math>\alpha = .94</math> (excellent) and negative VOL <math>\alpha = .83</math> (good).</p> <p><u>Inter-item correlation</u> <math>r = .55</math> for positive VOL and <math>r = .44</math> for negative VOL.</p>	<p><u>Indices of fit (AGFI):</u> .929 (good).</p> <p><u>Convergent:</u> Positive VOL correlated with scales of wellbeing, hardiness and mastery (range from .39 to .62). Negative VOL negatively correlated with scales of wellbeing and mastery (range from .47 to .67) All correlations were significant to <math>p &lt; .01</math> apart from autonomy, which was not significant.</p> <p>Positive VOL negatively correlated with depression (CESDD) (<math>-.37, p &lt; .01</math>)</p>	
	Attitude toward Aging Scale (AtA; von Humboldt, Leal, Pimenta, & Maroco, 2014)	<p>22 item, 7 point Likert scale.</p> <p>5 subscales: sense of purpose and ambition, zest and spirituality, body and</p>	<p>Portuguese community dwelling older adults (n = 1291) Mean age: 83.9.</p> <p>Participants were excluded if they scored 26 on an MMSE.</p>	<p><u>Internal Consistency</u> <math>\alpha = .891</math> for whole scale and range of <math>\alpha = .862- \alpha = .927</math> for subscales (good to excellent)</p>	<p><u>Construct:</u> Exploratory Factor Analysis (EPA) resulted in five-factor model fit explaining 75.6% variance. Negative and weak correlations with PANAS (<math>r = -.099, p &lt; .001</math>), Sense of Coherence-QtLQ (<math>r = -.202, p &lt; .001</math>)</p>	

		health, aging in place and stability and social support.				
Autonomy	Maastricht Personal Autonomy Questionnaire (MPAQ; Mars et al., 2014)	16 item, 5 point Likert scale. Three subscales.	Older adults with chronic physical illness (n =412, mean age: 70.25).	<u>Internal Consistency:</u> ICC: 0.61, 0.71, 0.80 for three subscales.	<u>Convergent:</u> MPAQ- degree of autonomy positively correlated (Pearson's) with Autonomy Visual Analogue Scale (0.71, $p < 0.001$ two tailed) and satisfaction with life (SWLS) (0.65, $p < 0.001$ two tailed). Negatively correlated with Impact on Participation and Autonomy Questionnaire (IPA) indoors (-0.54, $p < 0.001$ two tailed), family role (0.56, $p < 0.001$ two tailed), outdoor (0.68, $p < 0.001$ two tailed) and social relations (0.46, $p < 0.001$ ) two tailed.	
Sense of Coherence	Sense of Coherence Scale (Antonovsky, 1993)	29 item or 13 item (SF), 7 point semantic differential scale.	Jewish population. Details unavailable	<u>Internal Consistency:</u> Average of $\alpha = .91$ for 29 item and $\alpha = .82$ for 13 item (good).	<u>Face:</u> Feedback from experts.  Unable to establish convergent validity as the scale was novel.	<u>Validation study of 13-item in Dutch young adults with chronic illness:</u> (Luyckx, et al., 2012) (n =2781). 14-18 and 19-25 year olds scored lowest whereas 14-18 year olds with congenital heart disease and 26-30 year olds scored highest irrespective of gender.  A CFA resulted in items 5 and 6 being dropped. 3 subscales of meaningfulness, comprehensibility and manageability loaded onto a single second order factor, with factor loadings of .58, .93 and 1.00 respectively.

<b>Resourcefulness</b>	The Resourcefulness Scale for Older Adults (RSOA; Zauszniewski, Lai, & Tithiphontumrong, 2006)	28 item, 6 point Likert scale. Two subscales: personal resourcefulness and social resourcefulness	Older adults (n =451) Mean age: 81 Average of 3 chronic health conditions per participant.	<u>Internal Consistency:</u> Personal resourcefulness subscale: $\alpha = .84$ (good) Social resourcefulness: $\alpha = .80$ (good). Overall: $\alpha = .85$ (good)	<u>Confirmatory Factor Analysis:</u> Higher order factor analysis: single second order factor explaining 93.27% variance.	
<b>Combined Measures</b>	Control, Autonomy, Self-Realisation and Pleasure (CASP-19; Hyde, Wiggins, Higgs, & Blane, 2003)	19 item, 4 point Likert scale. Responses ranged from “0-Never” to “3-Often”	British older adults (n =286, age range 65-75).	<u>Internal Consistency:</u> Control: $\alpha = .59$ Self-Realisation: $\alpha = .77$ Pleasure: $\alpha = .74$ Autonomy: $\alpha = .67$ (all acceptable).	<u>Convergent:</u> Positive correlation with LSI-W ( $r = .63$ , $p = .001$ ).  <u>Factor Analysis:</u> All domains had strong factor loadings (.72 to .88) on a latent factor.	Used as a predictor of ‘quality of life’ so unlikely to be identified within the context of this review.

### 3.5 Discussion

It is debateable as to why so few positive psychology outcome measures have been developed for or validated in dementia populations, as there was no shortage of scales in populations identified as having shared characteristics within this review. This may be because of the prevailing medical model of diagnosing and treating dementia, despite the emergence of more person-centred models (Spector & Orrell, 2010), or it may be due to the continuing stigma surrounding the perception of dementia as a negative and debilitating condition, for which there is little to offer (Vernooij-Dassen, et al., 2005).

However, a wide range of measures were identified within the constructs of positive psychology that could be further validated for people with dementia. These included the CD-RISC for resilience, the GSWB, FACIT-Sp, and SIWB for spirituality, the SWLS and AtA for life valuation, the MPAQ for autonomy, the SOCS for sense of coherence, the RSOA for resourcefulness and the CASP-19 as a combined measure. However, for the constructs of self-efficacy, no suitable scales were identified. Although most scales identified scored moderately on a quality assessment, it is recommended that they are subject to further psychometric assessments, so that clinicians may better understand the potential role of positive traits within wellbeing for a dementia population. As the efficacy of non-pharmacological interventions within dementia has been established (Olazarán, et al., 2010), positive outcomes may aid the facilitation of more appropriate psychosocial intervention studies that aim to enhance quality of life.

#### 3.5.1 *Methodological Problems and Limitations*

Whilst an effort was made to include all-encompassing search terms, results often included outcome measures that were not indicative of positive psychology and the vast majority were subsequently excluded from the review on this basis. As in Chapter 2,

obtaining the original development paper of outcome measures was sometimes difficult and often accomplished through extensive searching of databases. For example, the SOCS proved difficult to obtain and an additional review of the measure was included in the review to more comprehensively assess its psychometric properties (Eriksson & Lindström, 2005).

It is important to acknowledge that 14 of the 16 scales were developed in American populations, the exceptions being the CASP-19, which was developed in a British sample and the AtA, developed in a Portuguese sample. As such it is questionable as to whether these scales are culturally appropriate for other populations as definitions of positive constructs may differ between cultures. However, of the 14 scales developed in American samples, six were translated into other languages and were validated appropriately, the most comprehensive of which was the SWLS, for which we identified three translations within the confines of this review.

The CASP-19 and the AtA were the only measures for which the authors reported a floor and ceiling effect, identifying the range of the scale, skew and kurtosis of results. It is recommended that future authors endeavour to report these factors. Only one scale of self-efficacy was identified for inclusion. The CRSES scored moderately at the quality assessment stage and no further validation studies were identified. Whilst there is a wealth of research measuring self-efficacy for caregivers of people with dementia (Gallagher, et al., 2011) there appears to be a lack of research concerning self-efficacy for people with dementia. This may be due to an absence of specific measures, developed for this population. As such, it is recommended that a domain specific scale of self-efficacy be developed and validated for people with dementia. Domain specific measures of self efficacy are often reported to have greater predictive ability and a



greater capacity to inform theoretical models (Bandura, 1977). Also of note was the MPAQ, a very recent scale, which scored 8/18 at the quality assessment stage. This scale was developed with older adults who reported a chronic physical illness and, therefore, represents two populations identified as being suitably similar to dementia within this review.

### ***3.5.2 Conclusion***

A wealth of positive psychology measures were documented within this review and were potentially translatable to dementia care. Therefore, in future development work, particular attention was paid to these concepts. Furthermore, as the CASP-19 received the highest score at the quality assessment stage and was developed specifically for older adults, it was deemed appropriate to assess the psychometric properties of this measure within a dementia population. Consequently, in addition to the development of new measures, the CASP-19 will be validated for people with dementia within this research.

## **4. Development of salient positive psychology concepts and generation of domains**

### **4.1 Introduction**

Whilst evidence for potential positive psychology that may hold psychometric utility for people with dementia was explored within Chapters 1 and 2, no conclusions could be drawn as to which positive concepts may hold more importance for people with dementia. As discussed within Chapter 1, positive concepts for people with dementia are currently lacking within the quantitative research, with only qualitative studies exploring such concepts. Once the domains to be measured have been identified, qualitative studies are recommended in order to generate items for measures (Velentgas, Dreyer & Wu, 2013). This enables a detailed examination of salient themes for the population in question, allowing concepts to be defined in ways that are most relevant to the population in question. For psychometric purposes, this ensures that measures have an adequate level of content validity (Allen & Yen, 1979).

### **4.2 Aims**

The aim of this chapter was to identify and examine positive psychology concepts that hold importance for people with dementia by means of consultation, literature reviews and the use of experts in the field and to systematically appraise existing measures of these concepts. Therefore, sub-aims of this chapter were to:

1. Develop a comprehensive list of positive psychology constructs that might be pertinent for people with dementia.
2. Explore these concepts and related measures.
3. Appraise existing measures of these concepts.

### 4.3 Methods

The current study followed an iterative process consisting of five steps and followed methodology recommended by Streiner and Norman (2008): Generation of positive psychology concepts, informal consultations, expert feedback, a literature review of salient concepts and an examination of existing outcome measures of salient concepts. Existing outcome measures of concepts were sourced either from reviews in Chapters 2 and 3 or by a separate systematic search if no measures were identified within the confines of earlier reviews.

#### *4.3.1 Generation of Positive Psychology Concepts*

To provide an all-encompassing list of positive psychology concepts, terms and definitions were extracted from a range of sources including current research, books and reviews (Hefferson & Boniwell, 2011; Nygren, et al., 2005; Seligman, 1998; Seligman, 2002; Seligman, Steen, Park, & Peterson, 2005; Wolverson, Clarke, & Moniz-Cook, 2016). These terms were synthesised into a table and circulated to members of the Promoting Independence in Dementia Research (PRIDE) team. PRIDE is a five year Economic and Social Research Centre (ESRC) grant awarded to Professor Martin Orrell at the University of Nottingham. The PRIDE team consists of a number of researchers and practitioners from differing backgrounds including clinical psychologists, nurses, former carers to a person with dementia and sociologists. PRIDE researchers were asked to comment on definition clarity and relevance. Furthermore, members of the PRIDE team were asked to provide additional terms they felt were relevant.

#### *4.3.2 Informal Consultations*

Three services that the researcher and primary supervisor had worked with before were approached via email with a speculative enquiry detailing the project at hand and asked

whether they might be interested in short informal discussions with the researcher.

These consisted of one care home and two day centres. Additionally, a former carer was contacted. All three services and the former carer indicated their interest, and a date was scheduled for the researcher to attend the service or visit the carer at their convenience.

Consultations were on an informal basis, to introduce the types of concepts people with dementia might hold in importance. As such, no ethical approval was obtained and no identifiable information could be recorded. However, where appropriate, participants were asked whether direct quotes could be noted.

People with dementia were asked whether they might like to talk informally about the personal strengths or characteristics they felt were important over the course of their life, particularly in the present. Health Care Professionals (HCP) were asked to give their opinion as to which positive constructs were most important for the people they cared for and to illustrate this with examples from their own experience of caring for people with dementia. The carer was asked this in relation to her late husband.

#### ***4.3.3 Literature Review of Salient Concepts***

In addition to evidence garnered within Chapters 2 and 3, salient themes were examined in the literature and within dementia literature to provide all-encompassing definitions and examine the potential applicability of concepts within dementia. PubMed, PsychINFO and Google Scholar were searched between 1998 - 2016 with identified terms from the informal consultations used as search terms. Following this, search terms were combined with terms denoting dementia and consisted of dementia, Alzheimer, cognitive impairment, senile, vascular. Truncations of search terms were used where appropriate.

#### ***4.3.4 Expert Feedback***

Conclusions from the informal consultation and literature review stage were presented to the PRIDE research team. The project also has Patient and Public Involvement (PPI) and a former carer was present for the presentation. Sixteen members of the PRIDE team were presented to and asked for feedback with regard to the importance of the constructs identified and were also asked to rank the most salient constructs in order of importance.

#### ***4.3.5 Examination of Existing Outcome Measures***

Using the evidence generated within the systematic reviews of Chapters 2 and 3, existing measures of concepts identified as important were examined for suitability. If no measure was identified within the confines of Chapters 2 and 3 for a concept that was deemed salient within the informal consultation and expert feedback stage, a further search of PubMed, PsychInfo, MedLine and CINAL between 1998 – 2016 was undertaken. Terms denoting salient concepts were combined with terms denoting outcome measures. These were instrument, quiz, test, questionnaire, inventory, index, scale, measure, and outcome. Concept and measurement terms were then combined with psychometric terms and consisted of development, validate, reliability, consistency, validity, properties, psychometric. Papers were included at this stage if they reported on the validation or development of an outcome measure. For those that reported on the validation of an outcome measure, the original development paper was sought. Following identification of suitable outcome measures, each were evaluated using processes outlined within Chapters 2 and 3 (Terwee, et al., 2007).

## 4.4 Results

### *4.4.1 Generation of Positive Psychology Concepts*

Literature searches resulted in 22 terms in need of operationalising and definitions were taken from published peer-reviewed journal articles and books. PRIDE researchers were satisfied with the clarity and relevance of terms and definitions provided but suggested five additional terms. These five terms were added to the definition list (Table 4.1).

### *4.4.2 Informal Consultations*

Broad themes were initially discussed with people with dementia until a number of concepts emerged as most salient. This resulted in a figure being developed to aid further informal consultations (Figure 4.1). Participants were presented with the figure (on A4 sized paper) and discussion was facilitated around which of the themes they felt were most important, what these concepts meant to each individual person and whether any concepts were missing from the figure.

A total of 19 people were consulted at this stage, consisting of 14 people with dementia, one carer and four health care professionals (HCPs). Conversations took place over the course of a two-week period (Appendix 1.1). People with dementia were either day centre attendees or residents at a care home. The one carer had cared for her late husband since his diagnosis of dementia until his death, and the four HCPs consisted of three health care assistants working at the care home and one training manager, also employed at the care home.

Table 4.1 Positive psychology concepts and definitions

Term	Definition
<b>Resilience</b>	A flexibility in response to changing situational demands. Or, the ability to ‘bounce back’ from adverse events or life experiences. It can be divided into three concepts: recovery, resistance and reconfiguration. Components of resilience include: reframing, experience of positive emotions, participation in physical activities, trusted social support, the use of personal and authentic strengths and optimism.
<b>Autonomy</b>	Ability to make decisions according to one’s own will. It refers to the capacity to make decisions independently, to serve as one’s own source of emotional strength, and to otherwise manage one’s life tasks without depending on others for assistance.
<b>Sense of Coherence</b>	A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable; (2) the resources are available to meet the demands posed by these stimuli and (3) these demands are challenges, worthy of investment and engagement. Consists of three components: comprehensibility, manageability, and meaningfulness.
<b>Independence</b>	Independence is the ability to act in accordance with one’s wishes and to perform activities without help from others. Thinking or acting for oneself. The state in which a person feels they can make free choices with or without support from others and maintain control over important aspects of their lives to sustain their selfhood.
<b>Social Participation/Engagement</b>	The extent to which an individual participates in a broad range of social roles and relationships. At a group level: the commitment of a member to stay in the group and interact with others. Components of social participation/engagement include: activity, interaction, social exchange and a lack of compulsion. In some of the literature it has been measured by questions such as: <ul style="list-style-type: none"> <li>- How often did you receive visitors at home?</li> <li>- How often did you visit others?</li> <li>- How often did you participate in social activities outside home?</li> </ul>
<b>Dignity</b>	An intrinsic and absolute value related to human worth and, as a subjective or relative value, related to a person’s experiences of how he or she is met and treated as a human being. It is often viewed as an important component of quality of life but term means different things to different people. It is sometimes described as being related to autonomy and integrity. Components in the literature (identified from meta-synthesis) include: compassion, empathy, confirming a person’s worthiness and sense of self, humane and purposeful environments.

<b>Self-Concept</b>	Distinction between continuous, coherent sense of identity that characterises normal human experiences and the types of self-knowledge that underpin this. Self-knowledge traits include: knowledge of traits, attributes, life history, roles and characteristics. Whilst subjective experience of identity cannot be directly quantified, forms of self-knowledge that contribute to a self-concept can be measured.
<b>Hope</b>	A feeling of expectation and desire for a particular thing to happen. Multi-dimensional concept involving future orientation, which is often goal focused. It can arise in the context of uncertainty or fear. Hope is emotional and, therefore, differs from optimism, which is more of a cognitive state. Motivational force that propels people.
<b>Optimism</b>	An attitude or world view that interprets situations and events as being best (optimised), so that in some way that may not be fully comprehended the present moment is in an optimum state. The concept is extended to include the hope that future conditions will unfold as optimal. Grounded optimism is defined as a person with a high expectation of success (a subjective estimation about the probability of achieving goals or desired outcomes) which is supported by other concepts such as self-efficacy.
<b>Self-efficacy</b>	The belief that one can reach one's goals or desired outcome. Or, the perceived ability to successfully manage the demands of a specific situation, with self-efficacy determining how people think, feel and motivate themselves.
<b>Coping</b>	Changing cognitive and/ or behavioural efforts that are activated to manage demands that are appraised to be surpassing the resources of the individual. Coping mechanisms have generally been divided into problem focused and emotion focused although the importance of contextual factors is noted.
<b>Wisdom</b>	The ability or result of an ability to think and act utilising knowledge, experience, understanding, common sense, and insight. Or, the coordination of knowledge and experience and its deliberate use to improve well-being
<b>Pleasure</b>	Refers to a broad class of mental states that humans and other animals experience as positive, enjoyable, or worth seeking. It includes more specific mental states such as happiness, entertainment, enjoyment, ecstasy, and euphoria. It is highly subjective with individuals experiencing different levels of pleasure in the same situation. Often measured using Lawton's Modified Behaviour Stream.
<b>Self-realisation</b>	Fulfilment by oneself of the possibilities of one's character or personality. Or, psychological growth, which represents the awakening and manifestation of latent potentialities. Has overlap with self-actualisation.
<b>Agency</b>	Agency refers to the subjective awareness that one is initiating, executing, and controlling one's own volitional actions in the world. The social model describes agency as when people act to influence their own personal circumstances; they exercise agency.



<b>Gratitude</b>	The feeling or attitude in acknowledgment of a benefit that one has received or will receive. Can be defined as an adaptive psychological strategy and an important process by which a person interprets their everyday experiences positively.
<b>Happiness</b>	A mental or emotional state of well-being characterized by positive or pleasant emotions ranging from contentment to intense joy. Seligman described happiness as arising when concepts including pleasure, engagement, relationships and meaning are satisfied.
<b>Self-Transcendence</b>	An expansion of one's boundaries inwardly in various introspective activities, outwardly through concerns about others and temporally, whereby the perception of one's past and future enhance the present.
<b>Humour</b>	The tendency of particular cognitive experiences to provoke laughter and provide amusement. It is a cross cultural concept that can be verbal, visual or physical. Humour can be seen as a specific defence mechanism by which positive emotions operate to reduce the undesirable negative emotions involved in a stressful situation.
<b>Creativity</b>	The process of producing something that is both original and worthwhile. The cognitive processes involved in creativity tasks may be distinguished into several components, such as application of knowledge, analogy, combination of elements, and abstraction, as well as into domain-specific components, such as visual restructuring. In addition, creativity also relies on concepts such as motivation and emotions.
<b>Flow</b>	<p>The intense experiential involvement in moment-to-moment activity, which can be either physical or mental. Attention is fully invested in the task at hand and the person functions at her or his fullest capacity. It has direct ties with consciousness and is thought to be ideal for enhancing positive effect. Conditions needed to facilitate flow include:</p> <ul style="list-style-type: none"> <li>- Structured activity with clear goals and immediate feedback</li> <li>- Balance of challenges vs skills</li> <li>- Complete concentration</li> <li>- Sense of control</li> <li>- Transformation of time</li> <li>- Activity for the sake of activity</li> <li>- Personality style.</li> </ul>
<b>Spirituality</b>	No single, widely used definition of spirituality. Denotes a transformation. Used to be defined exclusively in relation to religion but now is more orientated to subjective experience and psychological growth. It may refer to almost any kind of meaningful activity or blissful experience. Can be used as a coping mechanism.
<b>Love</b>	A variety of different feelings, states, and attitudes that ranges from interpersonal affection to pleasure. It can refer to an emotion of a strong attraction and personal attachment. It can also be a virtue representing human kindness,

	compassion, and affection—"the unselfish loyal and benevolent concern for the good of another". It may also describe compassionate and affectionate actions towards other humans, one's self or animals.
<b>Compassion</b>	A process of connecting by identifying with another person. This identification with others through compassion can lead to increased motivation to do something in an effort to relieve the suffering of others. It is a deep and personal emotion involving the understanding of the emotional state of another and the urge to alleviate or reduce the suffering of another.
<b>Connectedness</b>	Measure of how people come together and interact. Involves quality and number of connections one has with other people in their circle of family, friends and acquaintances. Beyond an individual level, it involves relationships beyond an individual's social circle and to other communities.
<b>Personal Growth</b>	Activities that improve awareness and identity, develop talents and potential, enhance quality of life and contribute to the realisation of dreams and aspirations.
<b>Altruism</b>	Acting for the benefit of others, sometimes with cost to the self. A motivational state with the goal of increasing another's welfare. Generally, includes pro-social behaviour such as comforting, helping, sharing, cooperation, philanthropy and community service.



*Figure 4.1 Figure used in informal consultations*

#### 4.4.2.1 *Self-efficacy*

The most salient theme identified by people with dementia were aspects of self-efficacy including confidence in one's ability to remain as independent as possible and with regard to self-expression. On the advice of a clinical psychologist within the PRIDE team, self-efficacy was discussed as confidence in one's ability to do tasks, as it was felt that self-efficacy was not a commonly used term outside of psychology. With regard to independence self-efficacy, people with dementia often talked about the vital importance of feeling independent but knowing someone would be there if they needed it. This 'someone' was usually referred to as either family members or carers. The caregiver and all HCPs identified self-efficacy with regard to independence as being important. The caregiver felt that the feeling of remaining independent for as long as possible was important for her late husband and all the HCPs noted that this was often something that could be lost when a person is diagnosed with dementia and this could have an impact on an individual's self-concept and, consequently, their self-worth. An example given by a HCP was that during self-care they would encourage people with dementia to attend to their needs in whichever way they were able to and this would enable them to feel independent. An interesting concept, as outlined by a HCP, was that being given a diagnosis of dementia could result in people suddenly becoming, in their mind, an '*old person*'. The HCP felt that this could be an alien concept to an individual who had never identified with this particular group of people before. She felt that sometimes people with dementia often felt they had to conform to the expectations and behaviours of this particular group and this could contribute to a lack of independence. The HCP felt this behaviour could be reinforced by the taking away of previously held roles and responsibilities and this could result in a learned helplessness or depressive mood.

With regard to self-expression self-efficacy, people with dementia often talked about how difficult it was to articulately express themselves resulting in a lack of confidence and impacting upon their ability to socialise with others. People with dementia reported wanting to engage with those around them but sometimes lacking the confidence to do so. One person with dementia discussed the importance of being patient with oneself but also having someone there to assist them when experiencing language aphasia. HCPs also identified self-efficacy with regard to self-expression as important. For example, one care assistant noted that having the confidence to express oneself could often be lacking in the people they cared for and the HCP felt it was their responsibility to be patient and allow adequate time and encouragement to facilitate self-expression. Incidentally, some people with dementia also mentioned patience as a distinct concept but it was often in the context of being patient with oneself whilst completing tasks or articulating.

#### 4.4.2.2 Hope and Optimism

People with dementia also talked about hope and optimism at some length and both were defined varyingly. For example, one person with dementia defined this as *'looking ahead'*, another defined it as *'being cheerful and happy'* about things and a third defined it as *'wanting things to be alright in the end'*. However, most felt it was an important concept and that it contributed to a general feeling of happiness for themselves and for others. HCPs also highlighted its importance, with one HCP giving an example of person with dementia saying to her *'when I get better...'*. For the HCP, this illustrated a hopeful and adaptive nature and enabled a person with dementia to *'keep going'*.

#### 4.4.2.3 Other Concepts

Other concepts were mentioned sparingly. For example, three people with dementia, the caregiver and one HCP, mostly within the confines of a coping paradigm, discussed sense of humour. Examples included looking at the world with a sense of humour and humour as a mechanism for building rapport with people. Resilience was also mentioned and defined in varying ways with one person with dementia defining it as *'not being able to do it today but I'll do it tomorrow'* whilst another concluded it was *'being able to stand it if there's trouble'*. One HCP thought resilience was particularly apt for people with dementia as they often had to cope with their personal world changing as a result of the progression of dementia and resilience would be a key resource in adapting to this. The caregiver noted that whilst an individual could appear to be resilient, this could be confounded by memory deficits. The caregiver illustrated this by giving an example of her husband appearing to adapt to situations he struggled with but, when questioned about it, it became apparent to her that he had in actual fact forgotten these situations. She also noted that specific positive concepts such as self-efficacy, humour and gratitude could actually lead to an outcome of resilience rather than resilience being a distinct, measurable positive characteristic in its own right.

Religiousness or spirituality was only mentioned twice. One person with dementia was particularly religious and felt this was of vital importance in their life. They defined their religiousness/ spirituality as a lasting connection to God and that feeling God was on their side made their life easier. The caregiver mused that, although this was not an important concept for her late husband, religiousness/ spirituality may be closely linked with a feeling of connectedness and this would probably only be relevant for people with salient religious beliefs and deeply held religious identity.

Finally, of particular note was gratitude. Although some people with dementia talked about being grateful for the help they received from family and carers, it was mentioned sparingly and one HCP noted that, for her, gratitude had unfortunate connotations with pity. She elaborated on this further by suggesting that although gratitude was nice, one should not expect people to be grateful for your actions and that often HCPs had to get used to working without gratitude.

#### ***4.4.3. Literature Review of Salient Concepts***

Of those identified, the concepts of self-efficacy with regard to independence and self-expression, sociability/ connectedness, hope/ optimism and resilience appeared to be important to people with dementia, carers and healthcare professionals. For the literature review stage, the titles of concepts were changed to ensure the literature could be searched effectively. Independence self-efficacy, after a search of self-efficacy literature, was redefined as a ‘sense of independence’ in order to differentiate it from functional independence. Furthermore, self-expression self-efficacy, sociability and connectedness were grouped under one concept entitled ‘social world engagement’.

Perceived self-efficacy is an essential part of social learning theory and is defined as a judgement of one’s abilities to organise and execute a given type of performance that develops from external experiences and self-perception (Bandura, 1977). It differs from self-esteem as this concept is usually defined as a favourable or unfavourable attitude toward the self (Rosenberg, 1965) and “there is no fixed relationship between beliefs about one’s capabilities and whether one likes or dislikes oneself” (Bandura, 1997, p. 11). Self-efficacy can also be differentiated from a sense of coherence, which is defined as a “global orientation that expresses the extent to which one has a pervasive, and

enduring though dynamic feeling of confidence” that the world is orderable, demands posed are manageable and that life is meaningful (Antonovsky, 1987, p. 19).

#### *4.4.3.1 Sense of independence*

Promoting independence is widely accepted as a valuable outcome for the maintenance of wellbeing for people with dementia, decreasing the potential stress felt by carers and delaying nursing home entry (Spillman & Long, 2009). Increasingly, research is being conducted to maintain this independence through interventions including exercise (Hogervorst, Clifford, Stock, Xin, & Bandelow, 2012) and occupational therapy (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). However, independence appears to be operationalised as a functional ability; the ability to care for oneself without the assistance of others. Whilst this is certainly an area that is of importance for people with dementia, as their ability to complete activities of daily living decreases, it does not recognise the multifaceted and complex nature of independence.

Due to the nature of dementia, it is reasonable to suggest that full independence, without support from others, may not be an appropriate goal for this population. Rather, independence in dementia may reflect the importance of systems (Barker, 1968) or the mutual support between a carer and a person with dementia, in order to facilitate a level of independence that is beneficial to both.

A sense of independence or independence self-efficacy would, therefore, be defined as a state in one has the perceived ability to act in accordance with one’s wishes and perform activities without help from others. In the context of dementia, this may refer to whether one has the perceived ability to make free choices with or without support from others and maintain control over important aspects of one’s life in order to sustain



a sense of personhood. This also has social connotations as playing a part in one's social world may be a means of retaining a sense of independence.

#### *4.4.3.2 Social world engagement*

Playing a part in a social world may consist of components such as reciprocity and social connectedness. Reciprocity stems from equity theory (Adams, 1963), in which people pursue reciprocity in interpersonal and organisational relationships. In the context of social psychology, reciprocity refers to the response to positive interactions, with positive interactions (Fehr & Gächter, 2000). It is a concept that is distinct from 'cooperative' or 'altruistic' behaviours as the former refers to an expectation of material gain from their actions and the latter refers to an unconditional kindness. Reciprocity may have important implications for wellbeing, as although some people may not be physically or mentally able to reciprocate, a retained desire of wanting to be of use to others is often present (Osse, Vernooij-Dassen, Schade, & Grol, 2005). This concept has been applied to dementia research, with the desire of people with dementia to be in a reciprocal relationship with their carers, despite physical setbacks being proposed as a potential means of mitigating a loss of autonomy (Vernooij-Dassen, Leatherman, & Rikkert, 2011). It has also been identified as an important theme in forming and retention of friendships in nursing homes (de Medeiros, Saunders, Doyle, Mosby, & Van Haitsma, 2011). However, it has also been applied to carer burnout, in which carers feel they put more into relationships than they receive in return and this may lead to a depletion in emotional resources (Duffy, Oyebode, & Allen, 2009).

Social connectedness begins to emerge in adolescence and refers to a feeling of being 'human amongst humans'. It is characterised by a successful maintenance of companionship and affiliation without any threat to self-esteem, where an individual is

able to feel confident and comfortable in a larger social context than family or friends (Lee & Robbins, 1995). Potential negative consequences of a lack of connectedness can be: feelings of distance from others, inability or difficulty accepting societal roles, isolation, frustration and disappointment at failure of others to understand them (Lee & Robbins, 1998).

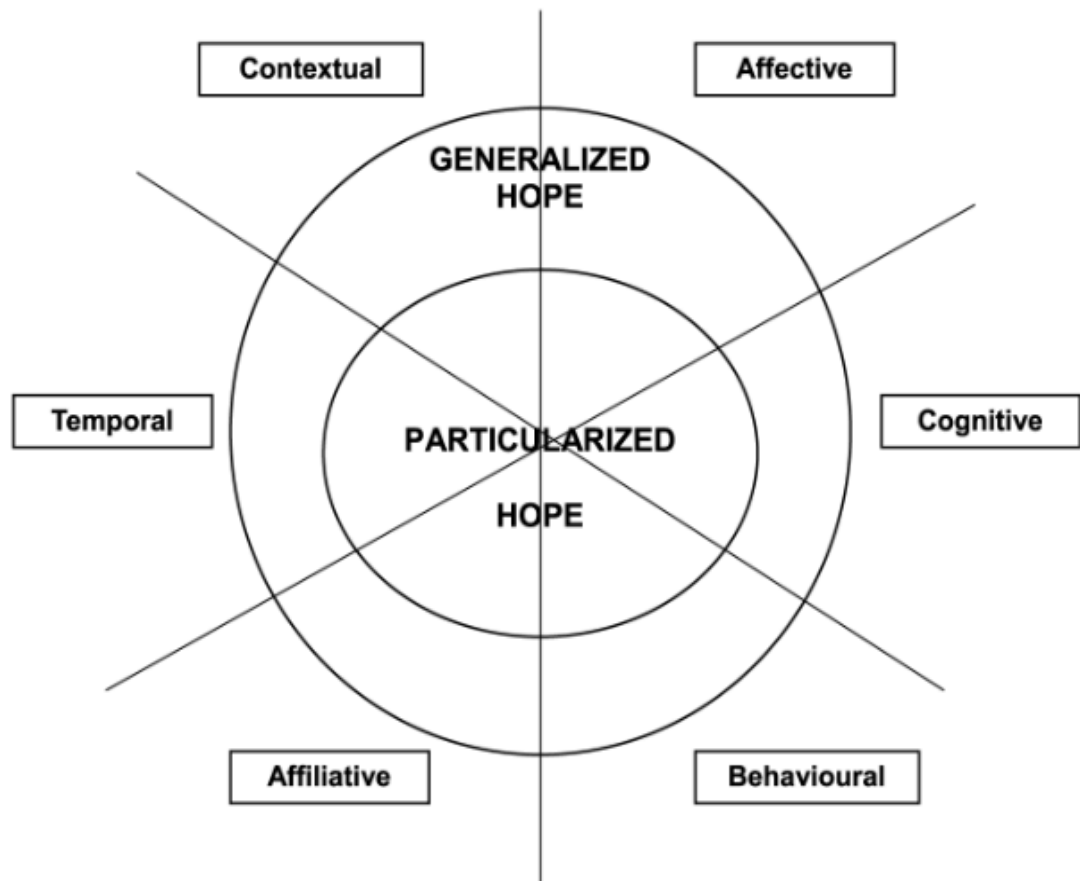
Both social engagement and reciprocity have been explored in other populations and have been found to have numerous health benefits including reducing risk of stroke (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005) and increasing psychological wellbeing for older adults (Park, 2009).

#### *4.4.3.3 Hope*

Hope and optimism, while interlinked, are distinct concepts. Previous work has indicated that, as optimism is often goal oriented, it may be less relevant for people with dementia due to the absence of hoped for goal related outcomes (Wolverson, Clarke, & Moniz-Cook, 2010). Therefore, hope was selected as the focus for this project.

Two theories of hope tend to dominate literature. Goal-directed hope, and multidimensional hope. Goal-directed hope is fuelled by the perception of successful agency related to goals and is usually defined as ‘a cognitive set that is based on a reciprocally derived sense of successful agency and pathways’ (Snyder, et al., 1991, p. 571). It is a sense of successful determination in meeting goals in the past, present and future and is influenced by a sense of being able to generate successful plans to meet goals. Goal-directed hope reflects the cumulative level of perceived agency and pathways and both of these factors are necessary, but neither is sufficient to define hope in isolation. In contrast to this theory is the conceptualisation of hope as a

multidimensional and dynamic life force that is characterised by confident yet uncertain expectation of achieving something good, which is realistically possible and personally significant (Dufault & Martocchio, 1985). It comprises of six different dimensions: contextual, temporal, affiliate, behavioural, affective and cognitive (Figure 4.2).



*Figure 4.2 Dufault & Martocchio (1985) model of hope*

Furthermore, Dufault and Martocchio (1985), theorised that hope can be particularised and general. Particularised hope is characterised by an expectation that what exists at the moment cannot be improved on, whilst generalised hope serves to preserve personal meaning and to protect against individual despair. Generalised hope is then a motivation to continue with life, which exists when a person is deprived of particularised hope.

Whilst both theories of hope have their merits they are distinctly different. Goal-directed hope assumes that hope is implicitly trait like and, therefore, stable across time and situation, with people either having high hope or low hope. It also has strong connotations with self-efficacy theory (Bandura, 1977) as efficacy and outcome expectancy parallel with agency and pathway. Multidimensional hope is more multifaceted, suggesting that hope can be present unencumbered by the presence of particular goals in the form of generalised hope.

A substantial qualitative study examined the presence and conceptualisation of hope for people with dementia, for which their findings provide a strong rationale for the applicability of multidimensional hope, rather than goal-directed (Wolverson, Clarke, & Moniz-Cook, 2010). For most, hope was described as an active process whereby a developmental history of ‘learned hope’ remains well preserved and this facilitated a process of ‘keeping going’, viewing difficulties encountered as challenges to overcome. Furthermore, there appeared to be an active re-appraisal of balancing hope and realism. This seems to indicate that for people with dementia, outcomes hoped for are grounded in realism and generalised in nature, as illustrated by themes of ‘keep living and living well’ and this is consistent with studies of older adults without dementia (Herth, 1993).

#### *4.4.3.4 Resilience*

Resilience is often used to describe those who display emotional stamina in adverse situations. Its definition is sometimes ambiguous and, therefore, operationalisations from differing theoretical standpoints were examined. Firstly, as a psychoanalytic construct, ego-resilience represents a dynamic capacity enabling people to modify their level of ego-control, in either direction, as a result of the demand characteristics within an environmental context (Block & Block, 1980). Secondly from a psychological

standpoint, resilience has been defined as a “dynamic process encompassing positive adaptation within the context of significant adversity” (Luthar, Cicchetti, & Becker, 2000, p. 543). Finally, resilience can be defined as “the flexibility in response to changing situational demands” (Tugade, Fredrickson, & Feldman Barrett, 2004). It is noted that whilst some definitions refer explicitly to an ‘adverse’ event preceding the development of resilience, the last definition presented refers to ‘changing situational demands’ as the precedent for resilience rather than an overtly negative event. A final important ambiguity with regard to resilience research is discussed by Richardson (2002), who noted that resilience could be operationalised as either a trait, a process or as an identification of motivational forces within individuals or groups.

Inter-related components that constitute resilience have been identified as: equanimity (a balanced perspective of life and experience), perseverance (a willingness to remain involved and reconstruct life), self-reliance (a belief in oneself and capabilities), meaningfulness (the realisation that life has a purpose and valuation of one’s contributions) and existential aloneness (a recognition that life paths are unique) (Wagnild & Young, 1990). However, resilience has also been conceptualised as more multi-faceted than this, consisting of a process of recovery, resistance and reconfiguration (Lepore & Revenson, 2006).

#### ***4.4.4. Expert Feedback***

Conclusions from the informal consultation and literature review stage were presented to the PRIDE research team by the primary researcher. Twelve members of the PRIDE team (six PhD students, one statistician, one health economist, two psychologists, one former caregiver, one music therapist) provided rankings of the concepts, and indicated that, from their experience, independence self-efficacy was the most important concept

for people with dementia, followed by hope/ optimism, social connectedness/ sociability, effective communication self-efficacy, and finally resilience. Generally, the PRIDE team felt that the concepts presented were all apt for people with dementia, although there was contention as to whether sociability represented a concept within the confines of positive psychology.

#### ***4.4.5 Reconciliation of Discussed Concepts with Positive Psychology Theory***

In an attempt to reconcile concepts discussed with positive psychology theory, a hierarchical map was created documenting potential relationships between concepts, higher order concepts and outcomes.

In Chapter 1, flourishing is discussed as an outcome comprising of positive emotion, engagement, positive relationships, meaning and accomplishment. It is suggested that these higher order concepts, in turn, may consist of lower order concepts such as hope and humour for positive emotion and connectedness, resilience and self-efficacy for engagement. However, attempting to reconcile lower order concepts with higher concepts or outcomes is problematic and a certain amount of overlap occurs. For example, in Seligman's theory (2011), happiness is classed as a positive emotion, leading to an outcome of wellbeing. However, within other theories such as Ryff (1989), happiness is described as the outcome of eudemonic wellbeing. Furthermore, lower order concepts such as connectedness could be categorised as either a form of engagement with those around you, or as an indication of positive relationships.

Furthermore, despite the potential similarities between quality of life and positive psychology, theorists tend to focus more on the concept of wellbeing rather than quality of life (Efklides & Moraitou, 2013). As such, it becomes difficult to integrate quality of

life within a conceptual map. It may be that quality of life is equatable conceptually to quality of life or that quality of life is a lower order concept that could be discussed as a pre-requisite to achieving wellbeing.

Figure 4.3 denotes an attempt to integrate the concepts discussed within positive psychology theories. Yellow boxes refer to outcomes, as discussed within respective theories and red boxes refer to the individual theories of happiness and consist of eudemonic happiness (Ryff, 1989), hedonic happiness and authentic happiness (Seligman, 2009). Blue boxes refer to higher order concepts that are deemed to comprise outcomes and green boxes refer to lower concepts that are measureable and may influence the higher order concepts. A green arrow depicts where lower order concepts are thought to impact upon higher order concepts.

#### ***4.4.6 Examination of Existing Measures***

##### ***4.4.6.1 Hope***

Two outcome measures of hope were identified in Chapter 2. Whilst the Adult Hope Scale (Snyder et al., 1991) scored more robustly in the evaluation, it is a measure of goal-oriented hope, rather than multidimensional hope. As the literature review stage suggested that multidimensional hope was more appropriate for people with dementia, the Herth Hope Index (HHI; Herth, 1992) was selected for use with people with dementia (Appendix 1.2).

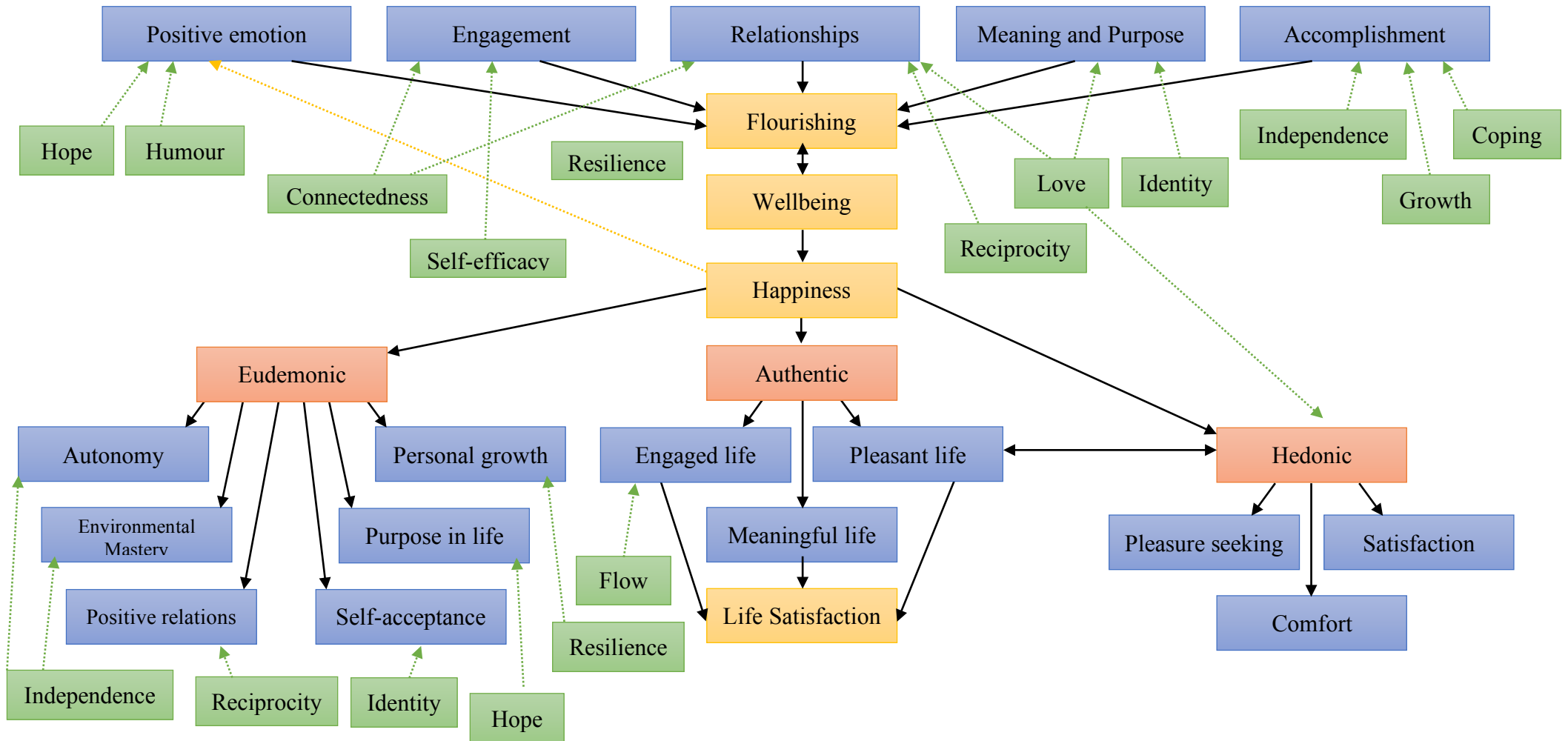


Figure 4.3 Conceptual hierarchy map



#### *4.4.6.2 Resilience*

A number of suitable scales of resilience were identified in Chapter 3 and, consequently, an additional quality appraisal was deemed unnecessary. Four scales measuring resilience were identified within the confines of the review: The Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003), the Brief Resilient Coping Scale (Sinclair & Wallston, 2004), the Resilience Scale (Wagnild & Young, 1993), and the Brief Resilience Scale (Smith, et al., 2008). Of these four, the CD-RISC and the Resilience Scale emerged as the most psychometrically robust, with a score of seven out of a possible 18.

#### *4.4.6.3 Sense of Independence and Social World Engagement*

No suitable measures for a sense of independence or social world engagement were identified as being suitable for potential use or adaption for people with dementia.

### **4.5 Discussion**

Using a five-stage procedure, salient positive concepts were identified as: a sense of independence, social world engagement, hope and resilience. A sense of independence was defined as a ‘state in which a person has the perceived ability to make free choices with or without support from others and maintain control over important aspects of their lives in order to sustain a sense of personhood.’ whilst social world engagement incorporated themes of reciprocity and connectedness. These themes may be inter-related as informal discussions of independence often revolved around the availability of support from others. No suitable outcome measures were identified here and so further development work was needed.

Whilst hope and optimism were mentioned interchangeably by people with dementia, hope was used during the literature review stage to ensure that the most appropriate term was used for the population in question. Previously hope within dementia has been regarded as purely a 'hope for a cure'. This discourse is compounded by societal views and negative media coverage in which a diagnosis of dementia is viewed as the worst possible tragedy, in which the person is lost (Behuniak, 2011). However, this was not supported in the current study as people with dementia expressed hope as generalised in nature.

Whilst it can be suggested that resilience is not an entirely positive concept, it was included in the current research due to its presence in discussions at the informal consultation level and in a recent systematic review of 'living positively with dementia' (Wolverson, Clarke, & Moniz-Cook, 2016). More specifically, this review of qualitative literature identified themes of engaging with dementia and 'facing it and fighting it' as a form of active perseverance through resilience. Furthermore, to exclude such a salient characteristic on the basis that it is not wholly positive could leave to a tyranny of positives in which potentially beneficial concepts for wellbeing were not examined.

A number of measures that may be appropriate for people with dementia were identified. Of these the HHI was selected as a potential measure of hope for people with dementia and the CD-RISC for resilience. Whilst the HHI was in the public domain and could be adapted, providing it was referenced appropriately, the CD-RISC was protected by strict copyright laws, prohibiting its use without a signed agreement and prohibiting any adaption work. To ensure that this was respected, further work was needed to fully develop a measure that was appropriate for people with dementia.

#### ***4.5.1 Methodological Problems and Limitations***

Data collection at this stage consisted of informal scoping. Originally, a qualitative measure development study had been planned and included in the PRIDE application to the Research Ethics Committee (REC). However, PRIDE represented a significant effort to bring together a large number of researchers and institutions across the UK. As such, the ethics application became increasingly delayed and it became evident that an application to the REC would not be ready for submission until much later in the year. Therefore, the decision was made to conduct an informal scoping exercise and, consequently, no identifiable information, audio-recordings or formal analysis could be conducted. Whilst this was not as methodologically rigorous as had been planned, it was decided that this course of action would allow measure development to move forward into more rigorous and methodologically sound research.

Whilst endeavouring to fully explore all positive concepts that people with dementia raised, time was limited and depended largely on the availability of people for discussions. Furthermore, those that elected to take part in such discussions may have been sociable in nature and this may have influenced results.

#### ***4.5.2 Conclusion***

Literature reviews, informal consultations and expert feedback resulted in four positive psychology concepts for people with dementia. Whilst suitable measures were identified for the concepts of hope and resilience, no measures were identified for social engagement and sense of independence. Therefore, further work was needed to adapt where appropriate and develop such measures for people with dementia.

## **5. The development of the Engagement and Independence in Dementia Questionnaire (EID-Q) and the Positive Psychology Outcome Measure (PPOM)**

(Stoner, Orrell, Long, Csipke & Spector, 2017)

### **5.1 Introduction**

Qualitative research alongside measure development improves the content validity of a novel measure and ensures it is an accurate tool to measure the domain in question (Rowan & Wulf, 2007).

As discussed in Chapter 4, promoting independence is widely accepted as a valuable outcome for the maintenance of wellbeing. Nonetheless, this is a relatively recent perspective. Work conducted nearly thirty years ago suggests that, although independence was valued, dependence was systematically enforced in a number of care homes (Baltes, Honn, Barton, Orzech, & Lago, 1983). As no suitable measures of this concept and that of social world engagement were identified in Chapters 2 and 3, a further qualitative study was warranted to operationalise the terms further and generate items for a proposed measure. Therefore, the majority of this study was focused on sense of independence and social world engagement.

Hope and resilience were also suggested as important concepts for people with dementia in Chapter 4 and measures of these concepts were identified in Chapters 2 and 3. However to ensure that measures had an adequate level of content validity, there was a need to consider if these measures required further development or adaption.

## 5.2 Aims

The aim of this chapter was to explore important positive psychology themes for people with dementia within a qualitative setting in order to generate items for outcome measures. As themes of ‘sense of independence’ and ‘social world engagement’ were identified in Chapter 4 and no suitable existing measure was identified, primary attention was paid to these themes. Therefore, the sub-aims of this chapter were to:

1. Explore the meaning of independence and social world engagement for people with dementia and explore how these concepts might interlink.
2. Generate items for a proposed measure of sense of independence and social world engagement.
3. Explore the meaning of hope and resilience for people with dementia.
4. Examine the applicability of existing measures of hope and resilience.
5. Generate items for measures of hope and resilience.
6. Consider adaption or further development work for measures of hope and resilience.

## 5.3 Methods

Methodology for the current study was split into two sections: qualitative analysis and expert feedback. Items for proposed measures were generated following completion of the qualitative study and then presented to experts for feedback and refinement. The use of experts is recommended in measure development as an aid to further improve content validity (Grant & Davis, 1997). Furthermore, content experts are recommended in the Terwee Criteria (Terwee et al., 2007) and have been used in previous measure development studies (e.g. Hyde, Wiggins, Higgs, & Blane, 2003).

### ***5.3.1 Qualitative Analysis***

#### ***5.3.1.1 Design***

A cross-sectional sectional qualitative design was used in which participants explored the meaning and implication of independence, social world engagement, hope and resilience in dementia. A topic guide and semi-structured interview format were used to facilitate discussion and elicit in-depth views on the subjective experience of these concepts.

#### ***5.3.1.2 Participants***

Ethical approval was obtained for the current study (15/EE/0134) and participants were recruited through one private organisation (a care home in Leeds) and an existing Cognitive Stimulation Therapy (CST) group within an outer London NHS trust between September and October 2015. The CST group was identified as an appropriate source of recruitment for the focus group, as it was an established group consisting of people with mild dementia. People with dementia, carers and healthcare professionals were interviewed separately either individually or within a focus group. Eighteen participants were approached and recruited for inclusion in the current study, all of whom met the inclusion criteria as detailed below:

People with a diagnosis of dementia according to the DSM-IV- criteria  
(American Psychiatric Association, 2000).

OR

People who identify themselves as an informal carer to a person with dementia.

OR

A healthcare professional who is employed in a dementia setting and has direct contact with people with dementia.

Participants were not included if they had a substantial disability or impairment that might limit their ability to participate. For example, participants were excluded if they had a substantial hearing impairment that could not be compensated for. The inclusion criteria for the current study was purposefully inclusive to maximise variability within subjective experience of concepts discussed. In the care home, care staff identified and initially approached suitable participants, and within the NHS site, the CST facilitator identified and approached suitable participants. All participants were provided with verbal and written information regarding the study. Carers were either identified as caring for members of the CST Group or via a voluntary service. All were approached by the lead researcher who provided verbal and written information.

#### *5.3.1.3 Procedure*

Potential participants were provided with an information sheet and consent form at least 24 hours before data was collected and participants were required to provide informed consent. All except one participant were able to provide informed consent. For this participant, a consultee assented on their behalf.

Interviews followed a semi-structured interview format that allowed interviewers to ask spontaneous questions that addressed individual circumstances. This ensured sensitivity to participant's self-expression with regard to constructing his or her own accounts.

Sessions were audio-recorded and discussion was facilitated around sense of independence, social world engagement, hope and resilience. Examples of questions asked were "how, if at all, has independence changed for you/ your relative?", "can you describe what hope means to you/ your relative?" and "what, if any, hobbies do you/ does your relative have?" Due to the logistical difficulty in gathering carers and

healthcare professionals in one space, individual interviews (some by telephone) were conducted with these participants.

Where appropriate, the Herth Hope Index (HHI; Herth 1992) was presented to participants to discuss any adaption work needed. To protect the copyright status of the Connor Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003) condensed examples of some item wording were presented to participants for discussion, as were full items from other scales in the public domain. Discussion was then facilitated at an item level.

#### *5.3.1.4 Data analysis*

Thematic analyses are iterative in nature (Braun & Clarke, 2006) and to reflect this, transcripts were analysed by the primary researcher and a research assistant independently. Initially, broad themes were generated to identify salient concepts. Following this, a consensus meeting was held in which researchers discussed their initial analyses. Any discrepancies between researchers were resolved through discussion with each other. Once agreement was reached, both researchers broad themes were synthesised into a table and refined into codes (Figure 5.1).

The primary researcher and the primary supervisor subsequently reviewed codes and disagreements were discussed until a consensus was reached. To limit researcher bias, data was independently reviewed and analytical notes of researchers own inferences were recorded. In this way, potential biases are documented and can be explored if necessary (Saldana, 2009).



To limit the possible influence of biases the following a priori assumptions were made about the topic as is recommended in qualitative research (Creswell, 1994). Firstly, it was assumed that a definition of independence might differ for those with dementia than those without and this may possibly be related to a decline in ability to complete activities of daily living (Giebel, Sutcliffe, & Challis, 2015). Secondly, it was assumed that social engagement might be linked to independence, based on previous work (Woods, 1999). Finally, people with dementia have the capacity to utilise character strengths, experience positive and supportive relationships and seek ways to maintain their identity (Wolverson, Clarke, & Moniz-Cook, 2016).

### ***5.3.2 Generation of Items and Expert Feedback***

Following completion of the qualitative study, items were generated for proposed measures using data gathered during Chapters 3 and 4 and from related measures of positive psychology. In the first instance, as many items were generated as possible to ensure accurate coverage. In this way, redundant items could be deleted at a later stage using psychometric analyses (Schepers, Orrell, Shanahan & Spector, 2012).

## **5.4 Results**

### ***5.4.1 Qualitative Analysis***

#### ***5.4.1.1 Participants***

The total sample was 18 (Table 5.1), of which five participants were recruited via the private sector, one was recruited from the voluntary sector and twelve were recruited from the NHS. Two focus groups for people with dementia were used (Group 1 n = 3; Group 2 n =6) and individual interviews were employed for carers (n =8) and one health care professional.

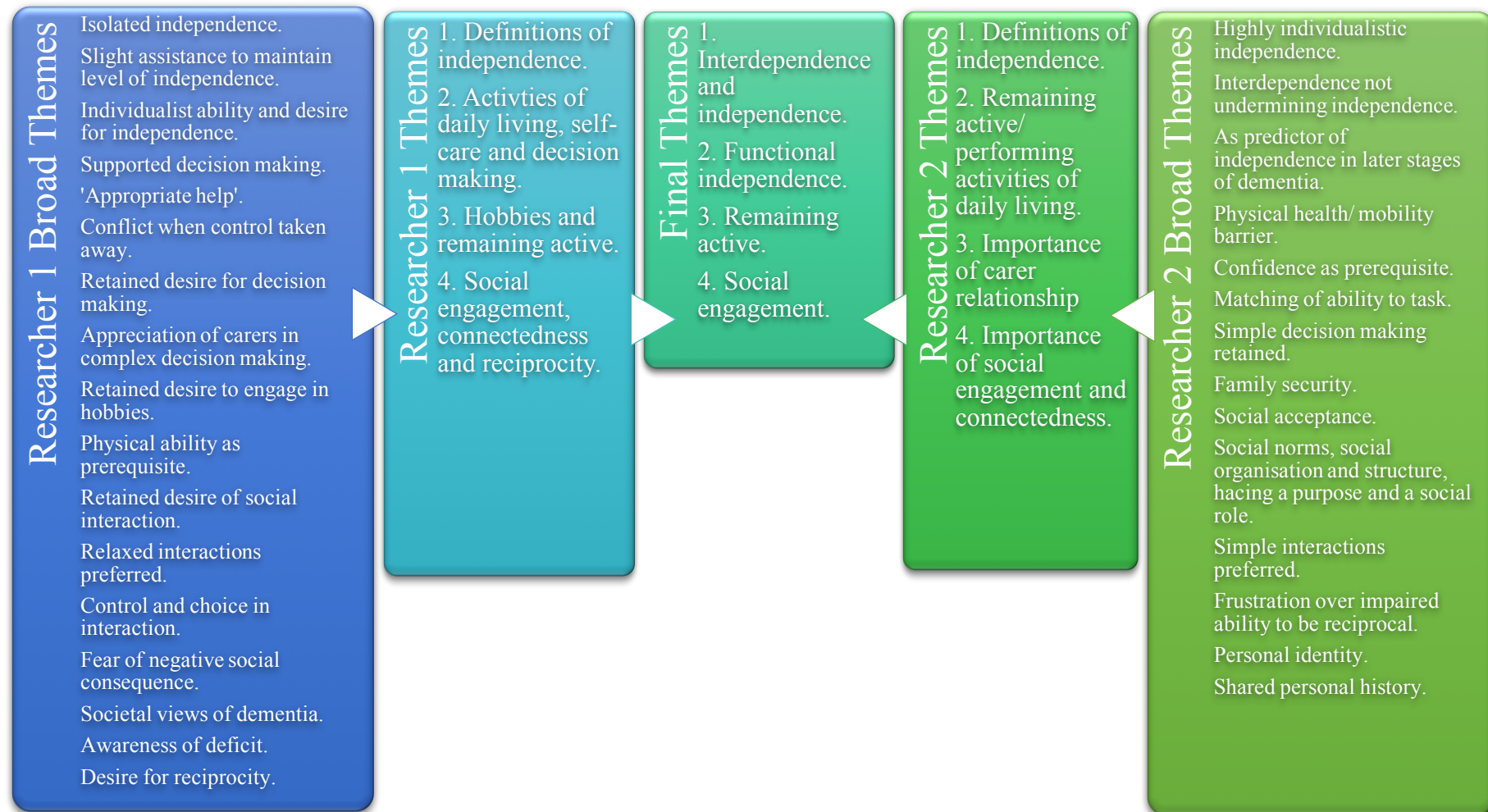


Figure 5.1 Synthesis of Independence and Social Engagement themes from qualitative analysis

*Table 5.1 Participant demographics in qualitative study*

	Total
Gender <i>n</i> (%)	
Female	16 (87.5)
PwD Age <i>M</i> ( <i>SD</i> )	80.56 (7.13)
Participant type <i>n</i> (%)	
PwD	9 (50)
Carer	8 (44)
HCP	1 (6)
Carer caring for <i>n</i> (%)	
Parent	3 (33)
Spouse	4 (44)
Grandparent	1 (11)
In professional capacity	1 (11)
Ethnicity <i>n</i> (%)	
White (British)	15 (83)
White (other)	1 (6)
Asian	2 (11)
Sector Recruited from <i>n</i> (%)	
Private	5 (28)
NHS	12 (66)
Voluntary	1 (6)

#### *5.4.1.2 Overarching themes*

Four overarching themes emerged as central to independence in dementia: 1) independence and interdependence, 2) functional independence, 3) remaining active and 4) social engagement. The first higher order theme illustrates ambiguity in definitions of independence in dementia and indicates that a period of interdependence between a carer and people with dementia can be beneficial for both. The second and third higher order themes reflect the differing domains within the concept of ‘independence’ and suggest that physical and mental ability may have important implications for the retention of independence. This was often compensated for with highly individualised support provided by informal carers and a constant reappraisal of abilities and task as a

person with dementia's ability to engage in such activities declined. The final higher order theme describes the retained desire of people with dementia to engage in social interaction with those around them and illustrates the barriers and facilitators to maintaining this engagement and its relatedness to sense of independence. A final theme of hope and resilience was also discussed (theme 5). These themes are described below using selected quotes to support their applicability.

*Theme 1: Independence and interdependence: Differing definitions within dementia*

General definitions of independence were often discussed by carers in the context of isolation: *'I think it's being able to do things by yourself maybe without the assistance of others or just being free to choose'* (C1). Regarding independence in dementia, definitions varied. Participants felt that independence changed as activities of daily living declined. This decline led to a person with dementia becoming more reliant on those around them and consequently participants, especially carers, revised their earlier definition of independence to one of apparent interdependence. This interdependence was often referred to as giving minimal assistance to people with dementia so that they could maintain a level of independence that suited their individual ability: *'Dressing and an occasional prompt... when the automatic is no longer automatic'* (C4).

However, two participants (carers) felt that independence was a universal trait and did not differ for people with dementia. These participants were also the only ones who believed that the person with dementia they cared for was not independent at all. These participants differed as they appeared to believe that, because a person with dementia was more likely to rely on those around them, they were not and could not retain their independence: *'if you're not even capable of... knowing what to do when you're hungry or anything like that then you are not independent'* (C3).

*Theme 2: Functional independence: activities of daily living, self-care and decision making*

Independence was discussed within the context of giving the 'right' level of support for a person with dementia. Too much could be frustrating for the person with dementia and too little could lead to the person with dementia feeling neglected. This was often discussed with regard to self-care: *'sometimes they can do it so it's quite right to, I think, leave them so they can still keep their independence' (H1)*. Carers often felt that, by adjusting the level of support given to a person with dementia based on their ability, it allowed people with dementia to focus on other decisions: *'yeah just having sort of basic needs assisted with and then you've got extra energy to focus on some other things that might be a bit more challenging' (C8)*. The potential for conflict occurred when the person with dementia felt that aspects of self-care were being taken out of their control but still wanted to make a decision even if this was, as seen by the carer, the wrong decision: *'If I say I don't think you should... wear that... It's not suitable for the weather. No he wants to wear it... if I don't let go he's very grumpy, upset' (C2)*. Furthermore, people with dementia talked about being hampered from doing activities for themselves. These could be due to safety concerns from the carer: *'But what annoys me is they don't let me do things I want to do' (P8)*. Often the desire to complete such activities was retained, with people with dementia choosing to satisfy this desire when carers were not present. A person with dementia, who talked about going for short walks when his wife was not home, illustrated an example of this. People with dementia also described a retained desire and satisfaction in decision-making: *'because I like to make decisions for myself. In a lot of places it's all right but as I said earlier on it not with some people ...' (P1)*. Some people with dementia noted that, until it happens, they would be unaware that their independence had been taken out of their control: *'Sometimes until it happens you don't realise that you are perhaps curbed from doing*

*things that you would like to do*’ (P1). However, this appeared to differ depending on domains. There was a general belief from carers that people with dementia were unable to make financial decisions: *‘I’ve never had to look after the money but I had to take all of that up’* (C7). Again, the desire to be involved was apparent as carers often discussed visiting the bank together and people with dementia reading bank statements. People with dementia often spoke about being appreciative of carers who took over complex tasks: *‘Are you happy for her to be in control?’* (Facilitator); *‘oh yeah. Good girl’* (P3). People with dementia also talked about the relief they felt that carers were there to assist them: *‘Oh yeah. If she wasn’t here I’d go round the bend. I think I would have topped myself’* (P8).

### *Theme 3: Remaining active*

As levels of independence decreased, complex hobbies were often abandoned *‘I got plenty (of hobbies) but I can’t do them now’* (P3) and people with dementia appeared to attribute this to physical ability. An example of this came from a participant who discussed being no longer able to fish: *‘I’ve got to roll myself over to a spot so that I can just get up and not join the fish... it’s impossible’* (P8). The consequences of losing hobbies once enjoyed were negative with one participant noting that it resulted in them feeling *‘sick’* (P3). Furthermore, people with dementia described missing activities once participated in: *‘those are the sort of things we used to do, you know? I miss that’* (P3). The consequences of having no hobbies were seen as negative by carers: *‘She has absolutely no stimulus anymore and that’s why she’s always looking out the window to see people going by’* (C3). Physical ability was discussed as a prerequisite for maintaining a suitable level of activity by people with dementia: *‘because I don’t go out... my legs. I like to go out and get on the bus to Romford... I couldn’t walk very far that’s the trouble with my legs’* (P5). People with dementia also saw activities as a

means of staving off boredom: *'you do don't you? She goes mad if there is nothing to do' (P1)*; *'Oh yes especially when we're stuck in all day in here and we can't go out for a walk' (P6)*. For carers, the need for people with dementia to engage in activities was seen as a form of mental stimulation: *'It must keep the bits of her brain that are still functioning more active than they are currently and that just cannot be a bad thing' (C3)*. Also, it was a way of promoting the self-worth of people with dementia: *'Activity means that... you're still important' (C5)*. Most felt that not being active was detrimental to people with dementia. Some carers likened not being engaged to fading away. This reinforced carers' desire for people with dementia to remain engaged and could often lead to prompting: *'My daughter will phone up and say have you done your walk mum?' (P4)*.

#### *Theme 4: Social engagement*

Aspects of social engagement were often discussed alongside independence. For example: *'Being able to make decisions yourself without bothering anyone else but at the same time taking their problems into concern' (P1)*. This engagement with others was also observed within focus groups, as participants often talked to each other and displayed insights into the other's personality: *'You know this is something I argue with her over all of the time. She said that well I can't. She can. She is ever so clever. You are ever so clever' (P1)*. Furthermore, these interactions appeared to be of a relaxed and superficial nature: *'we often say oh I'll pop out for an hour or so tonight. I won't stay long because I'm tired but we will sit and just talk generally about things... you feel fulfilled then at the end of the day and you don't need much if you're not talking about anything much' (P2)*. It was noted that people with dementia preferred to choose their own level of engagement: *'He was quite happy in a large pub where he could wander around and you know just chose who he would talk to but in a family grouping,*

*sometimes, he would just want to go for a walk because it was getting away from having to try and sort out who was who' (C1).* People with dementia often talked about their enjoyment of talking to other people and this was a view shared by carers: *'Oh yeah. It does mean a lot to me to be able to talk to people. It means a lot to me when I can express myself' (P2); 'If you've got things going on in your life and you've got interests, or you've got people around you as well...it does, I think, stave it off longer' (C5).*

Barriers to social engagement were usually discussed as a fear of negative social consequence or embarrassment. This could be because a person with dementia was aware of a deficit in language: *'I'd be thinking at the back of my mind what did you mean by that before I could explain myself you know, then it only just gets worse in my mind' (P1); 'I can't express myself that's my trouble. As to what I'm thinking. You want to know and I just can't do it... I can't stand up and speak like you are now' (P2).* Such awareness was observed by carers: *'He worries that he will say the wrong thing or won't remember something important and won't remember names or he'll get all flustered and won't be able to explain what it is he wants to say' (C6).* A further barrier to social engagement was explored with regard to other people's perceptions of the person with dementia and a fear for their safety. Examples included a carer whose late husband was often disinhibited in social settings. The carer expressed a constant concern that, in social settings, her husband would be punched as a result of his behaviour: *'So he said something that someone reacted to, you know, he could sort of go up and say or sing loudly when people are in the middle of a conversation' (C1).* People with dementia felt that those around them could be patronising in their attitudes: *'That's what I mean. Some people don't try and help and they're so patronising and you're making the person feel so small they're afraid of showing themselves up as well' (P1).* Carers noted that explaining behaviour to people took time but was often



appreciated: *'Just really explaining to people, not apologising, but you know just saying he has no control over this and if you find it difficult we'll go but it would be nice for us to stay' (C1).*

Connectedness and reciprocity were each linked to a sense of independence individually. This engagement was expressed as a feeling of being connected to children and grandchildren and often a desire for more contact. People with dementia were observed to talk fondly of time with their family: *'He'll phone me up on his mobile and say how are you Nan? You know, it's lovely' (P5).* Reciprocity was defined simply by one person with dementia as: *'Being kind to one another' (P1).* A desire to give back was also explored by carers who were aware of the person with dementia's desire to be reciprocal with them: *'He knows that it would please me and it would make me happier if he helped. This is why he does it. I wouldn't say it's his hobby' (C2).*

However, when a person with dementia felt they could not reciprocate, it could result in feelings of guilt and frustration: *'I mean bless his heart he says to me now I've ruined your life... he gets cheesed off at the fact his daughter is doing what I'm doing' (C5).*

This latter example was discussed in the context of a carer doing DIY chores around the house; something the person with dementia had been responsible for prior to the onset of dementia.

#### *Theme 5: Hope and resilience*

Saturation for hope and resilience data was reached very quickly. In line with previous work, people with dementia viewed hope generally and as being present on a day-to-day basis: *'Well I say I hope I get this and I hope I get that' (P1).* Resilience was discussed as a general strength that people with dementia felt was akin to standing one's ground in the face of difficulty: *'Take it as it comes unless you really clever and want to*

*do something but I'm not* (P2). This attitude of taking life as it comes was discussed with regard to various hospital appointments and health problems. As such, health related resilience might hold more importance than other aspects of resilience for this population and people with dementia noted the additional implications of ageing on health: *'the older you get the more difficult it becomes'* (P1).

When presented with items from the HHI for examination, the applicability of the item "I have short and/ or long range goals" was explored with the carer noting that this particular item might not be appropriate for people with dementia. The participant suggested that removing short and/ or long term from the item would make it more relevant. Furthermore, the meaning of the word "faith" in the hope scale was explored by the healthcare professional who felt it might be too ambiguous a concept: *'This may be too difficult question for people with dementia. Maybe they are at that age...Maybe but you can try it and see how it goes and if they can't really answer just cross out'* (H1). However, a participant suggested that the term being ambiguous was of benefit as people with dementia could define it in any way they wanted: *'I think you could still use...that because they'll make of it what they want, you know, that's the thing. Because I can't think of anything else...but whatever they come up with, that's their...so I'd keep it'* (C2). The applicability of future-oriented hope was also examined by one participant: *'I just read I feel scared about my future but maybe I don't know if it's further down but just on a day-to-day you are... just worried about the day or do you think that you know'* (C2). This may be particularly relevant for people with dementia, as participants with dementia did not express future-oriented hope. Whilst hoping for day-to-day outcomes, distant future-oriented hope was lacking. It therefore may be more relevant to amend this item to present rather than future hope. The participant noted example resilience items would be suitable and people with dementia would not find it difficult

understand such concepts. The healthcare professional described the items on the HHI and example resilience items as good but felt that they may be difficult for some people with dementia to complete.

#### ***5.4.2 Generation of Items and Expert Feedback***

To ensure the concept in question was accurately represented, as many items as possible were first generated. As such, thirty items were generated using the literature review of salient concepts, the results of the qualitative analysis, and an examination of related measures including the Maastricht Personal Autonomy Questionnaire (Mars et al., 2014) identified in Chapter 3 and the Lubben Social Network Scale (Lubben, 1988). This will hereafter be referred to as the Engagement and Independence in Dementia Questionnaire Version 1 (EID-Q V1)

Five members of the PRIDE team provided feedback on the EID-Q V1, consisting of a research fellow, two professors of old age psychiatry, a clinical psychologist and a senior research associate. All suggestions by the team were synthesised into one tracked changes document and most suggestions were acted upon. Amendments were largely regarding item difficulty, for example, ‘I can participate in groups/ activities with others’ was amended to ‘I can take part in groups/ activities with others’. Two items were removed as experts felt they were not relevant: ‘I can no longer make decisions’ and ‘I feel connected to society’. One expert commented that the overall length might be excessive. The remaining 28 items will hereafter be referred to as the ‘Engagement and Independence in Dementia Questionnaire Version 2’ (EID-Q V2; Figure 5.2).

- |   |
|---|
| 1. I can look after myself as much as I need to               |
| 2. I have people who I can talk to if I need to               |
| 3. I have hobbies/ activities that I enjoy doing              |
| 4. I have a role in my social circle                          |
| 5. There are things I would like to do but I can't            |
| 6. I take part in conversations in ways that I enjoy          |
| 7. I keep myself busy with activities/ hobbies                |
| 8. There are people I could ask for help if I need to         |
| 9. I am a burden to others                                    |
| 10. I have good relationships/ friendships with others        |
| 11. I can make my own decisions as much as I'd like to        |
| 12. I feel I am often ignored by those around me              |
| 13. I feel confident that I can make the right decisions      |
| 14. I feel connected to others                                |
| 15. I can do activities that are important to me              |
| 16. I can get in touch with friends/ family if I need to      |
| 17. I feel that people take decisions away from me            |
| 18. My friends/ family care about me                          |
| 19. I can arrange my life in a way that suits me best         |
| 20. I can help the people I care about                        |
| 21. I feel I am active in everyday life                       |
| 22. I can take part in groups/ activities with others         |
| 23. I can adapt my wishes to be in line with what I can do    |
| 24. I feel that my friends/ family want to spend time with me |
| 25. I can make changes to my life to match my abilities       |
| 26. I can confide in my friends/ family                       |
| 27. I can get myself food if I need to                        |
| 28. I can help my friends/ family as much as I would like     |

*Figure 5.2 Engagement and Independence in Dementia Questionnaire (EID-Q) Version 2 Items*

Hope and resilience represent traditional positive psychology and, therefore, it made theoretical sense to group these concepts under one measure consisting of 22 items, referred to hereafter as the Positive Psychology Outcome Measure Version 1 (PPOM V1). Items were adapted for the Herth Hope Index (HHI; Herth, 1992) and developed for the resilience subscale, using examples from existing resilience scales. Again, experts mainly suggested that items were in need of re-wording to improve clarity. For example, 'I am a strong person' was amended to 'I am an emotionally strong person' and 'I can see possibilities in the midst of difficulties' was amended to 'I can see

positive things in difficult situations’. No items were suggested as being unnecessary and no items were suggested as being needed. Items were re-worded following the advice of experts and will hereafter be referred to as ‘Positive Psychology Outcome Measure Version 2’ (PPOM V2; Figure 5.3).

1. I have a positive outlook on life
2. I feel all alone
3. I can see positive things in difficult situations
4. I have faith in the future
5. I feel scared about my future
6. I can recall happy/ joyful times
7. I have inner strength
8. I can give and receive care/ love
9. I have a sense of direction in life
10. I believe that each day has potential
11. My life has value and worth
12. I am able to adapt to things
13. I am able to deal with whatever happens
14. I am able to see the humorous side
15. I can cope with stress well
16. I can bounce back
17. I can achieve my goals
18. I can stay focused
19. I am not easily discouraged
20. I am an emotionally strong person
21. I can handle unpleasant feelings

*Figure 5.3 Positive Psychology Outcome Measure (PPOM) Version 2 Items*

#### **5.4.3 Format of the EID-Q V2 and PPOM V2**

To determine the format of measures a range of response options were discussed in the supervisory team. As the concepts in question were not considered to be absolute, dichotomous scales in which participants answered yes or no to each item were considered to not be appropriate. Likert scales are usually used in outcome measurement, for which people rate their strength of agreement on a scale format.

As the concepts in question appeared to be individualistic, varying between participants, a Likert scale was deemed to be most appropriate. However, as these concepts were

considered to be subjective and because of the nature of the population, Likert scales that referred to specific numbers and periods of time, for example, ‘once in the last week’ were also considered not to be appropriate. As such, a Likert scale that asked participants to rate how true an item was adopted for use (Figure 5.4).

‘Not true at all’	‘Rarely true’	‘Sometimes true’	‘Often true’	True nearly all the time’
0	1	2	3	4

*Figure 5.4 Likert Scale for PPOM V2 and EID-Q V2*

#### *5.4.3.1 Likert scales and parametric testing*

Data in Likert scales are usually referred to as ordinal as there is a clear ordering of response options but it is difficult to deduce whether or not the spacing between responses is equal, differentiating it from interval data. This assignment of numbers to each response is subject to debate, as Lord (1953, p. 751) pointed out “the numbers do not know where they come from”. This refers to the difficulty in arbitrarily assigning numbers to each response with the difference between strongly disagree and disagree, for example, assigned 0 and 1 without being able to accurately differentiate the specific conceptual difference between strongly disagree and disagree. Consequently, it becomes a conceptual issue of interpreting differences or similarities in the underlying concept based on the numbers each response is assigned.

There is also a substantial debate surrounding the statistical analysis of Likert scale data with some advocating parametric analysis and others advocating non-parametric analysis. Both approaches have advantages and disadvantages. Non-parametric tests do not operate under the assumption of a normally distributed population but do require increased sample sizes. Parametric tests, conversely, do work under the assumption of a

normal distribution but have the same level of power as non-parametric tests with a lower sample size (Sullivan & Artino, 2013).

As positive concepts have not been examined quantitatively for older adults with dementia, there is no evidence to support or contend that such concepts follow a normal distribution, violating the assumptions of parametric testing. However, with a substantial review discussing the use of parametric testing on Likert data it was concluded that the belief parametric tests would reach erroneous conclusions when assumptions were violated was over-exaggerated as parametric tests are “incredibly versatile, powerful and comprehensive” (Norman, 2010, p.627). Furthermore, the author concluded that, whilst most researchers referred to the distribution of data, in actuality the assumption of normality applies to the distribution of the means and Central Limit Theorem dictates that for samples greater than five or 10 per group, means are approximately normally distributed, regardless of original distribution. In addition to this, historically, tests such as Pearson’s R correlations have been shown as robust using highly skewed and non-normal data concluding that this parametric test remains insensitive to extreme violations of basic assumptions of normality and type of scale (Havlicek & Peterson, 1976). It is, therefore, appropriate to use parametric tests on Likert type data.

## **5.5 Discussion**

One positive psychology measure was developed (EID-Q V2) and one adapted and developed (PPOM V2). A balanced methodology employing focus groups, individual interviews and the use of experts resulted in a rich data set. Focus groups allowed the elicitation of in depth discussions between participants and individual interviews

allowed each participant to express their opinion, something some people find uncomfortable in a group setting.

### ***5.5.1 Sense of Independence in Dementia***

Independence in dementia is presented as complex and often other concepts were incorporated into discussions, therefore presented a challenge in developing a suitable outcome measure. Such concepts included remaining active and aspects of social engagement including connectedness and reciprocity. Remaining active has been noted as potentially beneficial in the maintenance of independence for people with dementia (Lucia & Ruiz, 2011).

Sense of independence appeared to be presented as a spectrum; as people with dementia's ability to complete daily activities and self-care declines, carers began to take over complex tasks while leaving the person with dementia able to make simple decisions. This period of interdependence was often appreciated by the person with dementia but conflict arose where there was disagreement between three components: a person with dementia's own perception of their ability, a carer's perception of the person with dementia's ability and the person with dementia's actual ability. If a carer assumed too much control, leaving a person with dementia unable to remain as independent as they believed they were capable of, it could lead to frustration felt by the person with dementia and carer stress. Furthermore, it could result in excess disability with the person with dementia feeling helpless and more dependent on the carer than they would otherwise be.

Results from this study would appear to indicate that independence is variable rather than fixed for people with dementia. It appears to consist of a process of re-evaluating



the level of independence a person with dementia is capable of and wants, which is necessary to maximise the period in which interdependence is beneficial to both the person with dementia and carer's wellbeing. Participant accounts were consistent with previous research into independence with dementia in that interdependence appeared to be preferred and a reality for both carers and people with dementia (Woods, 1999).

### ***5.5.2 Social World Engagement***

Social engagement appeared linked to independence and was viewed variably, with participants preferring differing levels of contact. It, therefore, appeared that people with dementia, like most people, retained a desire to maintain engagement with others. This variation may be attributable to pre-morbid personality of the person with dementia.

Increasingly, the aim of psychosocial research for people with dementia is to maintain independence through interventions including exercise (Hogervorst, Clifford, Stock, Xin, & Bandelow, 2012) and occupational therapy (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). However, in these studies independence is defined in varying forms and usually as a functional ability, for example, the time taken to walk from one place to another or the ability to dress, both without the assistance from others. Whilst there appears to be an implicit expectation that improving independence will increase wellbeing, the observed relationship can be ambiguous (Baines, Saxby, & Ehlert, 1987).

The current study used definitions of independence as discussed by people with dementia in a qualitative setting and as such, the EID-Q V2 may provide a more holistic measure of a sense of independence, rather than a measure of an operant capability.

Social connectedness refers to the experiences of belonging and relatedness to others (van Bel, Smolders, Ijsselsteijn, & de Kort, 2009). For people with dementia, this may refer specifically to close family as these relationships become more and more interdependent. It is also suggested that reciprocity is implicitly related to the concept of interdependence in dementia. For example, in the current study, people with dementia often demonstrated an awareness of deficits, which either led to appreciation of the carer or frustration if they felt they were unable to be reciprocal. This perception of an inability to be reciprocal has previously been noted as a factor in carers experiencing psychological distress (Ablitt, Jones, & Muers, 2010).

The importance of the relationship between a person with dementia and carer has previously been explored with a reciprocal relationship being highlighted as an important feature (Førsund, Skovdahl, Kiik, & Ytrehus, 2015). This reciprocal relationship refers to the ability of the person with dementia to provide assistance to their carer in ways that they feel are beneficial to them, in exchange for the carer providing means of assistance to them. Reciprocal relationships have been found to have numerous health benefits including reducing risk of stroke (Boden-Albala, Litwak, Elkind, Rundek, & Sacco, 2005) and increasing psychological wellbeing for older adults (Park, 2009).

### ***5.5.3. Hope and Resilience***

Accounts of hope in the current study were consistent with previous findings in which future-oriented hope appeared to be less appropriate for people with dementia (Wolverson & Clarke, 2016) and accounts of resilience appeared to support the definition of adapting to changing situational and personal demands. Resilience, as a positive psychology trait, is not without contention. However, positive psychology

seeks to provide a balance and to exclude such a salient characteristic could lead to a tyranny of positives in which potentially beneficial concepts for wellbeing are not examined, because it is not seen as a completely positive trait.

#### ***5.5.4 Methodological Problems and Limitations***

Focus groups were hampered by time constraints, with the second group only running for 30 minutes, due to the time taken to complete the consenting procedure. The second group benefited from the presence of an additional facilitator, whose prior knowledge of the participants aided focused discussions. However, it is noted that this prior knowledge may have introduced some bias. Furthermore, participants in groups had a tendency to talk over each other and as such, transcribing small sections of data proved challenging.

The sample was limited in that people with dementia were predominantly white, female and the average age was 80.56. It is possible that experiences of independence differed in terms of culture, gender and age and future studies may wish to address this.

Additionally, the carer sample was homogenous in nature, all being female, and the majority White- British. Four participants cared for a spouse, three for a parent and one for a grandparent. These factors may have influenced the experience of independence in the current study.

Finally, the current study primarily included people with mild dementia who were capable of giving informed consent. As such, this study can make inferences regarding independence in earlier stage dementia but is unable to make assumptions about the longitudinal impact, particularly in those with later stage dementia for whom increasing dependence is an actuality. This is an area of enquiry that requires further exploration.

#### ***5.5.5 Conclusion***

Two positive psychology outcome measures were developed using a series of informal consultations, qualitative analysis and expert feedback. This resulted in the PPOM V2 and EID-Q V2 ready for piloting with a sample of people with dementia.

## **6. The piloting of the PPOM and the EID-Q, and the initial validation of the CASP-19**

(Stoner, Orrell, Long, Csipke & Spector, 2017).

### **6.1 Introduction**

The PPOM V2 and EID-Q V2 were developed using processes in Chapters 4 and 5, whilst the CASP-19 was identified in Chapter 3 as requiring validation for people with dementia. As part of measure development, it is recommended that outcome measures are subject to a small pilot before being used in larger scale studies (Baker, 1994). This ensures that newly developed measures can be checked for preliminary psychometric properties and helps to identify redundant or difficult items. Furthermore, it can identify methodological issues and enable changes to be made to study designs before larger evaluation.

### **6.2 Aims**

The aim of this chapter was to appraise the psychometric properties, feasibility, clarity and readability of novel measures in an internal pilot (n =33). In order to accomplish this, the following sub-aims were to:

1. Conduct a preliminary psychometric evaluation of the PPOM V2, EID-Q V2 and CASP-19.
2. Appraise feasibility of conducting the study as either by interview or by self-report.
3. Identify methodological issues.

### **6.3 Methods**

#### ***6.3.1 Design***

The internal pilot was an observational, questionnaire-based study in which participants were asked to complete the PPOM V2, EID-Q V2 and CASP-19, in conjunction with additional measures discussed later. Participants could elect to complete the study by self-report or by interview.

#### ***6.3.2 Participants and Sample Size***

To be eligible, participants had to meet the following inclusion criteria:

- 1) Established diagnosis of dementia according to DSM-IV criteria (American Psychiatric Association, 2000).
- 2) Capacity to give informed consent.

On average, 30 participants are required to estimate a parameter in a reliability pilot study (Brown, 1995). As such, a recruitment target of 30 was set. Participants were people with dementia residing either in the community or within a care facility in Kent and were patients identified within North East London NHS Foundation Trust (NELFT).

#### ***6.3.3 Recruitment***

Participants were recruited within voluntary organisations within Kent (Cogs Clubs; Tuppen, 2015) and a charity within Essex (Tapestry; Tapestry Care UK, 2015) and at NELFT between February 2016 and April 2016. Recruitment took place through the Join Dementia Research website (JDR), memory services, CST groups, day centre services and voluntary organisations including Cogs Clubs and charities such as Tapestry. The JDR is a joint initiative from the National Institute of Health Research

(NIHR) and Alzheimer Scotland, Alzheimer's Research UK and the Alzheimer's Society. It is a website that encourages people with dementia and carers to register their details, in order for them to see research in their area and express an interest in taking part in such research. Researchers are able to register their study on the website and are informed if a potential participant has expressed an interest in participating. Participants were also recruited via carers services including carer days at NHS organisations and voluntary organisations. Recruitment strategies were designed to target both the person with dementia and their family carer.

#### *6.3.3.1 Recruitment procedure*

Written and verbal information was distributed or presented to potential participants. The research team attended memory clinics, CST groups, carer groups and events, within NHS organisations and within the community (Appendix 2.1 – 2.2). Information regarding the research including eligibility criteria and lay summaries were provided to healthcare professionals who were asked to refer participants they thought might be eligible and interested in participating, provided they had discussed with referral with the participant first.

Contact details of the primary researcher were made available to people with dementia and carers interested in finding out more information about the study. If the person with dementia had given their consent to being contacted, the research team contacted them to give further information either by telephone or post, depending on their preference.

#### *6.3.4 Screening and Consent Procedures*

A member of the research team screened participants against the eligibility criteria either over the telephone or in person. If a person with dementia was unsure of their

specific diagnosis, permission was sought to ask their carers this and verified where necessary, with the participant's permission, by accessing healthcare records from the database used by the NHS trust. Before capacity to provide consent was ascertained, people with dementia and carers were provided with written information regarding the study and had the opportunity to ask questions of the researcher and discuss withdrawal procedures, data confidentiality and the manner in which they would prefer to complete the study. All participants were made aware that their participation was voluntary and that no disadvantage would befall them if they chose not to participate, that they were free to withdraw from the study at any point without giving a reason and this would not affect their healthcare or legal rights.

To establish capacity to give informed consent, established guidelines (The British Psychological Society, 2010; Department of Health, 2005) were followed. Participants were deemed able to provide informed consent if they were able to understand, retain and provide a verbal summary of information regarding the study including its purpose and what participation entailed. The research team at the NHS site was responsible for conducting informal capacity assessments and if there was any uncertainty regarding capacity, it was discussed within the research team until a decision was made.

Following the establishment of capacity, participants were asked to sign a consent form (Appendix 2.3) and were given a copy of the consent form to keep for their own records.

If a participant declined to answer one or more items on the measures, the research team respected this. In no instances were participants encouraged to answer questions they did not feel comfortable with. Furthermore, if at any point the participant expressed a



desire to terminate the assessment, the research team again respected this and the assessment was paused or terminated.

### ***6.3.5 Data Collection Procedures***

The research team all had current good clinical practice certificates and were trained research assistants, nurses or clinical studies officers with experience of working with people with dementia. The venue in which the participants completed the study varied according to their needs but was mostly completed in the participants' home. People with dementia could complete the study in two ways: by interview or by self-report. Participants were presented with both of these options and encouraged to choose which method they preferred. These procedures are discussed separately below.

#### ***6.3.5.1 Interview procedure***

A suitable date, time and venue for a member of the research team to visit the person with dementia were agreed upon, with the input of their carer if appropriate. Lone working procedures at each NHS trust were followed if the researcher was attending the venue alone. Following consent procedures, participants were read out items on each questionnaire and responses available on the Likert scale. Researchers were encouraged to read at a pace the participant appeared comfortable with and take breaks as and when they felt the participant wanted or needed them. The pace of assessments varied between participants but generally took approximately 30 minutes. All researchers were encouraged to conduct assessments with understanding and empathy and respond appropriately to any disclosures that presented a risk to participants (e.g. suicidal ideation, abuse or criminal behaviour). If, at any point, a participant became distressed or expressed a desire to pause or terminate the interview, researchers paused or terminated assessments accordingly. Most interviews were conducted in the presence of

a carer, however, if the research team felt that the carer was unduly influencing the participant's answers, the research team re-iterated that it was the participant's opinion that they needed to record. This was done in a respectful manner that recognised most carers were attempting to aid the person with dementia to give the 'correct' answer.

#### *6.3.5.2 Self-report procedure*

A suitable date and time was arranged with the person with dementia, and their carer when appropriate, to telephone the participant to assess capacity to give informed consent. The information and consent form was discussed and a decision was made on the person's competence in answering questions. If capacity was established, participants were sent out the appropriate forms with a pre-paid stamped and addressed envelope and instructed to complete the study and then post it back to the research team. Where possible, the participant was telephoned to ensure that they had received the forms and were given advice or assistance on answering the questions if necessary.

#### **6.3.6 Outcome Measures**

Outcome measures booklets were designed and distributed to all participants. A complete copy of the outcome measures booklet, including versions two of both the PPOM and EID-Q can be found in Appendix 4.1. Trust logos were added for participating NHS trusts, as per their instruction.

##### *6.3.6.1 Demographic information*

Participants were asked to provide details on their date of birth, marital status, ethnicity, specific dementia diagnosis and date of diagnosis, details of co-morbid health conditions including depression or terminal illness. They were also asked which, if any,

anti-dementia medication they were currently taking and details of other psychotropic medication including medications for depression and anxiety.

#### *6.3.6.2 Positive Psychology Outcome Measure Version 2 (PPOM V2)*

PPOM V2 is a 21-item measure, rated on a 5-point Likert scale (0 ‘Not true at all’ to 4 ‘True nearly all the time’) and consists of two subscales: hope and resilience. The hope subscale was an adaption of the Herth Hope Index (HHI; Herth, 1992) and the resilience subscale was developed during Chapters 4 and 5.

#### *6.3.6.3 Engagement and Independence in Dementia Questionnaire Version 2 (EID-Q V2)*

The EID-Q V2 is a 28-item measure, assessed on a 5-point Likert scale (0 ‘Not true at all’ to 4 ‘True nearly all the time’). It measures a person with dementia’s sense of independence and levels of social engagement with those around them. The EID-Q V2 was developed in Chapter 5.

#### *6.3.6.4 Control, Autonomy, Self-realisation and Pleasure (CASP-19; Hyde, Wiggins, Higgs, & Blane, 2003)*

The CASP-19 is 19-item measure rated on a 4-point Likert scale (0 ‘Never’ to 3 ‘Often true’). It was developed from a theoretical standpoint of humanistic psychology (Maslow, 1943) and has strong connotations with positive psychology. It was developed for use in older adults and the result of a second order factor analysis indicated strong loadings for a single, underlying quality of life factor. The CASP-19 was identified in Chapter 3 and, whilst it has adequate psychometric properties, the CASP-19 has yet to be validated with people with dementia (Stoner, Orrell, & Spector, 2015).

*6.3.6.5 Quality of Life in Alzheimer's Disease (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999)*

Quality of life was selected to measure convergent validity of the novel measures due to the theoretical relationship between positive concepts and quality of life examined in the qualitative literature. More specifically, it is suggested that a discussion of life in a more positive narrative contributed to a person with dementia feeling more content with their life (Steeman, Godderis, Grypdonck, De Bal, & De Casterlé, 2007).

The QoL-AD is a brief 13 item measure on a 4-point Likert scale, with scores ranging from 13 to 52. Higher scores indicate a better quality of life across domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. It has an acceptable reported level of internal consistency (0.77-0.84) and has demonstrated convergent validity with other quality of life and health related measures (Wolak-Thierry, et al., 2015). It was designed to be self-report and the scale can be completed even for those with more severe dementia (Thorgrimsen, et al., 2003).

*6.3.6.6 Geriatric Depression Scale 15 (GDS; Sheikh & Yesavage, 1986)*

Depression was selected as an additional measure of convergent validity as it is suggested that concepts including hope and resilience may act as a protective in the development of depression. The role of resilience as protective has been examined in older adults and an association between greater resilience and less depressive symptomology has been documented (Wermelinger Ávila, Granero Lucchetti, & Lucchetti, 2016).

The GDS is a 15-item measure with yes and no responses. It is designed to be self-administered, although questions may be read out if required. A score of 10 or higher indicates depression (Sheikh, & Yesavage, 1986). The GDS has been validated for people with dementia (Leshner & Berryhill, 1994) and is sensitive to change in older adults (Vinkers, Gussekloo, Stek, Westendorp, & van der Mast, 2004). The GDS was selected due to its brief completion time and tested psychometric properties in people with dementia.

### ***6.3.7 Ethical Approval***

The study was entitled the Positive Psychology Outcome Measures for people with dementia (PPOM) and was reviewed and approved by the East of England: Essex Research Ethics Committee (15/33/0443). Ethical approval was granted on the 8<sup>th</sup> February 2016 (Appendix 3.1) and the study was given support by the National Institute of Health Research (NIHR) Central Portfolio Management Scheme (CPMS ID: 30348). Confirmation of insurance from University College London (UCL) was obtained on the 12<sup>th</sup> October 2015 (Appendix 3.5).

## **6.4 Results**

### ***6.4.1 Participant Demographics***

38 people with dementia were approached to take part. Of these, four lacked capacity to consent and one declined to take part. All remaining 33 participants had been diagnosed with dementia and were deemed capable of giving informed consent (Table 6.1).

Participants were predominantly female with a mean age 80 years and ages ranged from 58 to 94 years. Just over half of the participants reported their marital status as

widowed, with the remainder either reporting that they were married or that they were divorced. The majority of participants resided in the community with only three participants within residential or care facilities. Participants were also predominantly white British, with Black and Minority Ethnic groups (BME) only accounting for three participants.

*Table 6.1 Participant demographics for pilot study.*

	Total
Gender <i>n</i> (%)	
Female	19 (57.6)
Age <i>M</i> ( <i>SD</i> ) Range	80.18 (8.27) 58-94
Marital status <i>n</i> (%)	
Married	14 (42.4)
Widowed	17 (51.5)
Divorced	2 (6.1)
Residing <i>n</i> (%)	
Community	30 (90.9)
Residential Facility	3 (9.2)
Ethnicity <i>n</i> (%)	
White (British)	28 (84.8)
White (other)	2 (6.1)
Black	1 (3)
Asian	2 (6.1)

#### **6.4.2 Participant Clinical Characteristics**

Table 6.2 reports the clinical variables of participants. Participants were predominantly diagnosed with Alzheimer's disease or dementia of mixed aetiology. Eight participants were unaware of the specific type of dementia they had been diagnosed with.

Participants reported having lived with dementia for a varying amount of time.

Seventeen participants were not currently taking cholinesterase inhibitors, with the remainder either taking donepezil, memantine rivastigmine or galantamine. The

majority of participants were not currently taking other psychotropic medication with the exception of six participants who were taking an anti-depressant.

*Table 6.2 Participant clinical characteristics for pilot study*

	Total
Dementia diagnosis <i>n</i> (%)	
Alzheimer's Disease	13 (39.4)
Vascular Dementia	5 (15.2)
Dementia of mixed aetiology	7 (21.2)
Unknown sub-type	8 (24.2)
Time since diagnosis <i>n</i> (%)	
<1 year	8 (24.2)
1- 2 years	3 (9.1)
2- 3 years	8 (24.2)
>3 years	6 (18.2)
Unknown	8 (24.2)
Cholinesterase inhibitors <i>n</i> (%)	
None	17 (51.5)
Donepezil	4 (12.1)
Other	12 (36.4)
Other psychotropic medication <i>n</i> (%)	
None	27 (81.8)
Anti-depressant	6 (18.2)

#### **6.4.3 Correlations between Measures and Norms**

Positive correlations were found between the resilience subscale on the PPOM V2 and both independence and engagement subscales on the EID-Q V2 ( $r = .480, p = .007$ ;  $r = .392, p = .032$ ) respectively and with the overall measure ( $r = .466, p = .010$ ).

Furthermore, the hope subscale on the PPOM V2 was observed to be correlated with both the independence and engagement subscales ( $r = .451, p = .011$ ;  $r = .567, p = .001$ ) respectively and with the overall EID-Q V2 ( $r = .520, p = .003$ ).

#### 6.4.3.1 Norms of the PPOM V2

Possible scores on the PPOM V2 were from 0- 64, and reported scores ranged from 34 to 60. The observed mean was 50.94 (7.215 SD) and the median was 53. Analysis of skew and kurtosis indicated a negative skew (-.868) and a slightly flat distribution (-.112) (Figure 6.1).

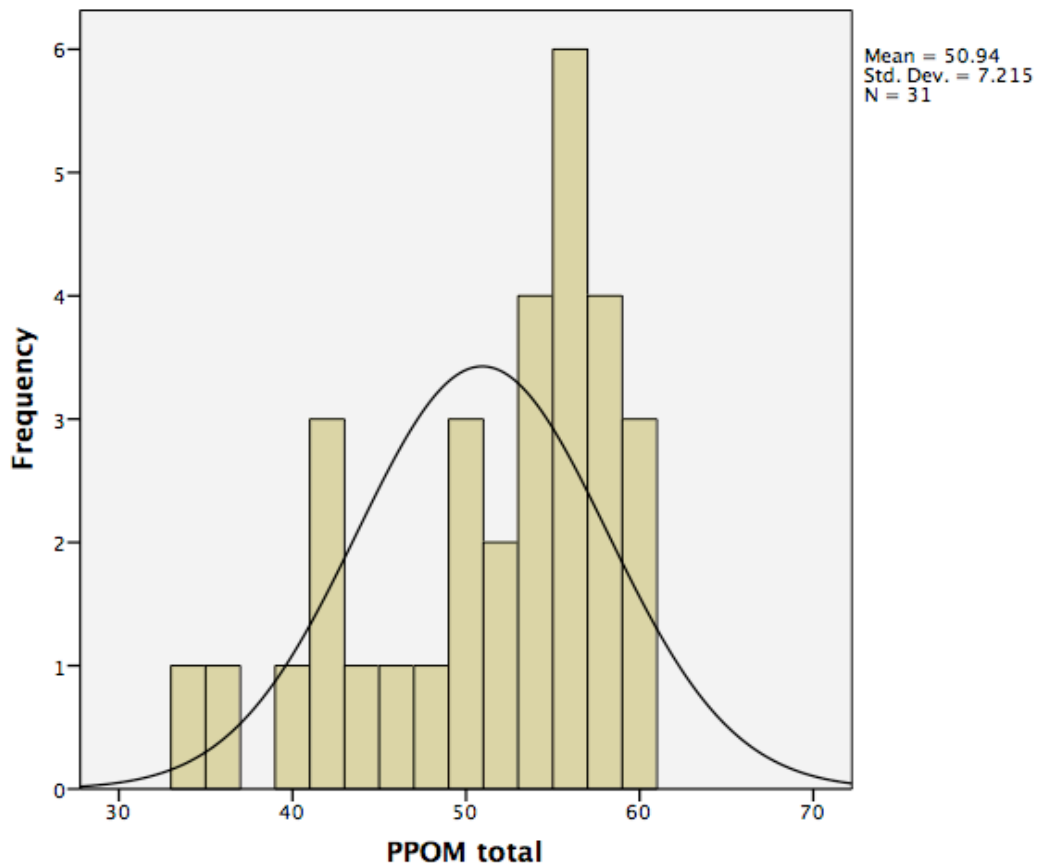


Figure 6.1 Distribution of the PPOM V2 for pilot study

#### 6.4.3.2 Norms of the EID-Q V2

Scores on the EID-Q V2 can range from 0, indicating a complete lack of independence and social engagement, to 104 indicating maximum levels of independence and social engagement. In the current study, scores ranged from 45 to 104, with a mean of 86.55 (14.240 SD). Again, results indicated a negative skew (-.976) but a more peaked distribution (.879) (Figure 6.2).



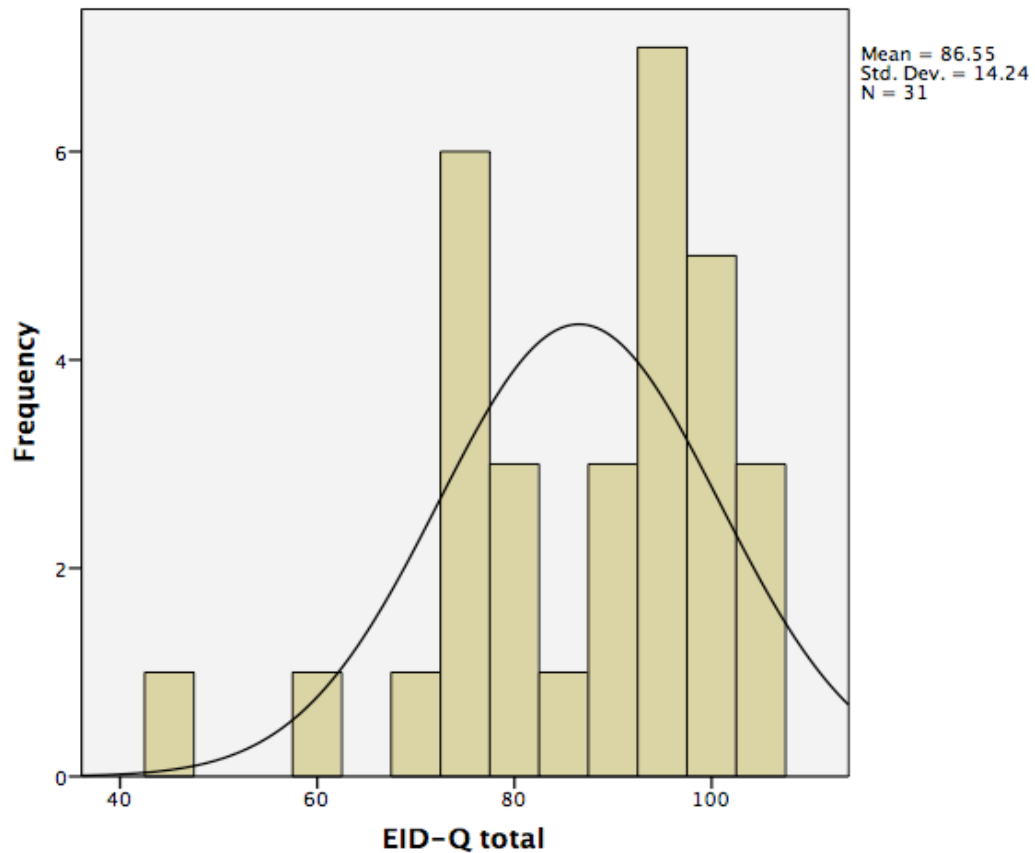


Figure 6.2 Distribution of the EID-Q V2 for the pilot study

#### 6.4.3.3 Norms of the CASP-19

Scores on the CASP-19 can range from 0, which represents a complete absence of quality of life, to 57, which represents complete satisfaction across the four domains. In the current study, scores ranged from 35 to 55 with a mean of 44.39 (6.07 SD) and median of 44. Results indicated a mostly symmetrical distribution of data, with a slight positive skew (.166). However, results indicated a flatter distribution than found in the original data (kurtosis: -1.260) (Figure 6.3).

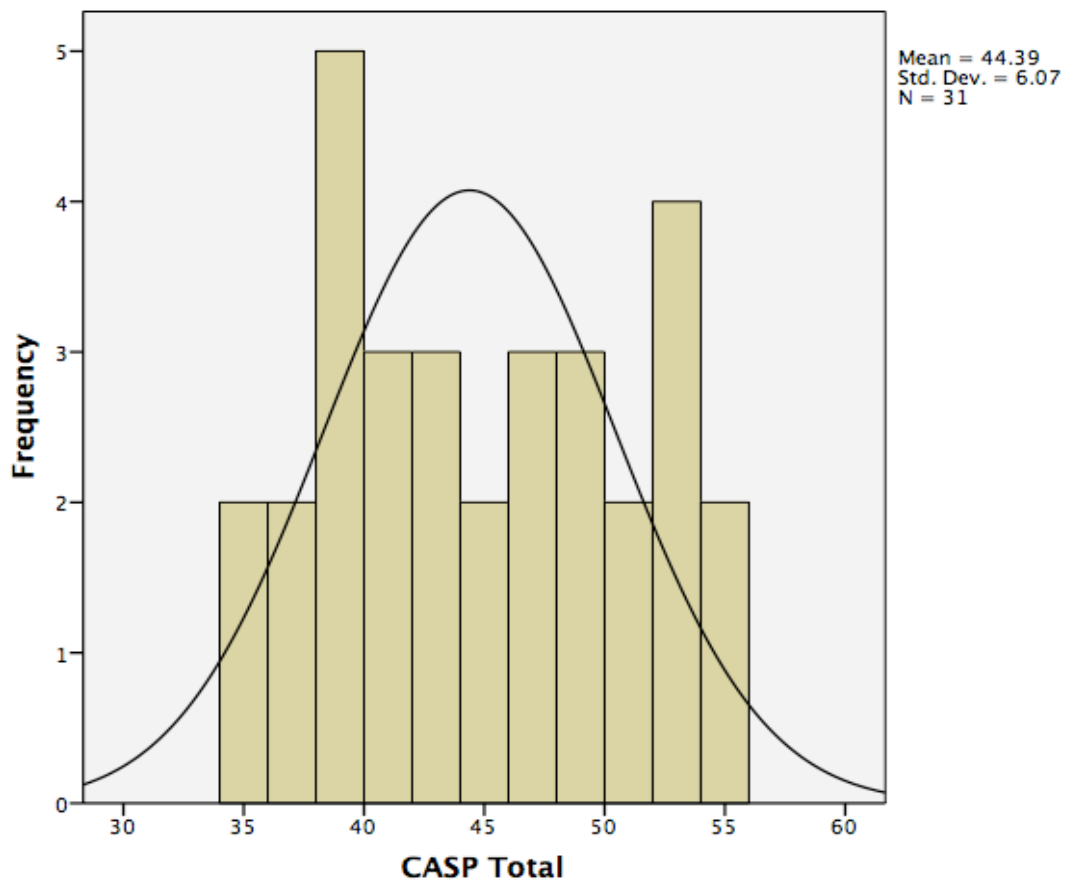


Figure 6.3 Distribution of the CASP-19 in the pilot study

#### 6.4.4 Psychometric Properties of the PPOM V2

##### 6.4.4.1 Internal Consistency

The first internal consistency analysis revealed that the PPOM V2 had an overall Cronbach alpha level of  $\alpha = .793$ , and the subscales were  $\alpha = .859$  for resilience and  $\alpha = .557$  for hope. This highlighted that one or more of the items may not be pertinent for people with dementia.

Following further analysis, it emerged that the removal of three items on the hope ('I feel all alone'; 'I have faith in the future'; 'I feel scared about the future';) subscale and two items on the resilience subscale ('I can achieve my goals'; 'I am not easily discouraged') would improve the internal consistency of the PPOM V2 (Table 6.3)

After removing these items, the overall internal consistency improved to  $\alpha = .849$ , with the subscales improving to  $\alpha = .755$  for hope and  $\alpha = .871$  for resilience. This resulted in a 16-item scale, consisting of a hope subscale (8-items) and resilience subscale (8-items).

*Table 6.3 Internal consistency of the PPOM V2 for the pilot study*

	<b>Original (no. of items)</b>	<b>After 1<sup>st</sup> deletion (no. of items)</b>
<b>Hope Alpha</b>	.557(11)	.755 (8)
<b>Resilience Alpha</b>	.859 (10)	.871 (8)
<b>Total Alpha</b>	.793 (21)	.849 (16)

#### *6.4.4.2 Convergent validity*

Preliminary indications of convergent validity were found between the PPOM V2 and the GDS. A two-tailed Pearson's R correlation was performed, finding negative correlations. More specifically, a moderate negative correlation was observed between the hope subscale and the GDS ( $r = -.557, p = .001$ ), and a significant correlation was observed between the PPOM V2 and the GDS ( $r = -.562, p = .002$ ). However, the resilience subscale was not significantly correlated with total scores on the GDS ( $r = -.312, p = .088$ ).

An additional Pearson's R correlation was performed to assess the relationship between scores on the QoL-AD and the PPOM V2. However, no significant correlations were observed between these measures, possibly indicating that hope and resilience are distinct from quality of life.

### 6.4.5 Psychometric Properties of the EID-Q V2

#### 6.4.5.1 Internal consistency

Initially the EID-Q V2 had an adequate level of internal consistency ( $\alpha = .896$ ) and the subscales were of sufficient value ( $\alpha = .849$  for independence and  $\alpha = .771$  for engagement). By removing two items from each subscale ('there are things I would like to do but can't'; 'I am a burden to others' for independence and 'I have good relationships/ friendships with others'; 'I feel I am often ignored by those around me' for engagement), the overall internal consistency was raised to  $\alpha = .916$  and subscales were raised to  $\alpha = .883$  for independence and  $\alpha = .801$  for engagement (Table 6.4).

However, it was noted that by removing reverse coded items from the scale, response bias might be introduced. To limit this, one reverse coded item from each subscale was re-integrated into the EID-Q V2 ('I am a burden to others' for independence and 'I feel I am often ignored by those around me' for engagement). The internal consistency analysis was re-run and indicated an acceptable internal consistency for both independence and social engagement subscales and the overall measure ( $\alpha = .868$ ,  $\alpha = .775$  and  $\alpha = .907$  respectively).

*Table 6.4 Internal consistency of the EID-Q V2 for the pilot study*

	<b>Original (no. of items)</b>	<b>After 1<sup>st</sup> deletion (no. of items)</b>	<b>After item re-integrated.</b>
<b>Independence Alpha</b>	.849 (14)	.883 (12)	.868 (13)
<b>Engagement Alpha</b>	.771 (14)	.801 (12)	.775 (13)
<b>Total Alpha</b>	.896 (28)	.916 (24)	.907 (26)

#### 6.4.5.2 Convergent validity

As with the PPOM V2, a two-tailed Pearson's R correlation was performed for both subscales and the EID-Q V2 scale and the GDS. Significant correlations were found between the independence subscale ( $r = -.447, p = .012$ ) and GDS, the engagement subscale ( $r = -.430, p = .016$ ) and the GDS and the EID-Q V2 and the GDS ( $r = -.461, p = .009$ ). This again indicated a negative correlation between the sense of independence, social engagement and depression.

Pearson's R correlations between the EID-Q V2 and the QoL-AD indicated an emerging positive relationship between independence, engagement and quality of life. Firstly, the total QoL-AD score was found to be positively correlated with the independence subscale ( $r = .497, p = .005$ ), engagement was correlated with the QoL-AD ( $r = .586, p = .001$ ) and the EID-Q V2 was found to be positively correlated with the total QoL-AD score ( $r = .557, p = .001$ ).

### 6.4.6 Psychometric Properties of the CASP-19

#### 6.4.6.1 Internal consistency

An internal consistency analysis was performed on each of the domains in the CASP-19 and the overall measure. Firstly, the control domain was found to have an alpha of  $\alpha = .433$ , secondly, autonomy was found to have an alpha of  $\alpha = .520$ , thirdly, pleasure was  $\alpha = .439$  and finally, self-realisation was  $\alpha = .632$ . The overall internal consistency was found to be  $\alpha = .678$ . As the domains fell below the acceptable limit, further analysis was necessary. Total scores for each of the four domains were summed and Pearson's R correlation were performed to establish whether there were significant relationships between domains (Table 6.5).

Table 6.5 Correlation coefficients of the CASP-19 for the pilot study

	Control	Autonomy	Self-realisation	Pleasure
Control	1			
Autonomy	.446*	1		
Self-realisation	.302	.239	1	
Pleasure	-.120	-.139	.406*	1

\*correlation is significant at .005 level (2-tailed).

Table 6.6 Correlation coefficients of CASP-19 (Hyde, Wiggins, Higgs, &amp; Blane, 2003)

	Control	Autonomy	Self-realisation	Pleasure
Control	1			
Autonomy	.648**	1		
Self-realisation	.463**	.345**	1	
Pleasure	.667**	.556**	.558**	1

\*\* $p = .01$

Of the four domains, significant positive correlations were observed between control and autonomy and also self-realisation and pleasure. Again, this was lower than observed in the original development study (Table 6.6).

#### 6.4.6.2 Convergent validity

Pearson's R correlations between the CASP-19 and GDS indicated a negative relationship between quality of life and depression ( $r = -.574, p = .001$ ). Both the control and autonomy subscales were also significantly correlated with depression ( $r = -.451, p = .010$ ;  $r = -.460, p = .008$ ).

#### 6.4.6.3 Concurrent validity

As the CASP-19 is a quality of life measure, it should theoretically be linked to scores on the existing and validated QoL-AD. A Pearson's R correlation between total CASP-19 scores and total QoL-AD scored indicated a positive correlation between these

measures ( $r = .590, p = .001$ ) and both the control and self-realisation subscales ( $r = .517, p = .003; r = .461, p = .010$ ).

#### ***6.4.7 Feasibility Data***

##### *6.4.7.1 Missing data*

Of the sample, eight participants elected to complete the study by interview. For this subsample, only one item of missing data was recorded for one participant and this was due to the participant not feeling able to answer the item ‘I have faith in the future’ requesting that it be left blank. This item was found to be redundant during the internal consistency analysis and was subsequently removed. The remaining 25 participants elected to complete the outcome measures by self-report but had a much greater instance of missing items (Table 6.7). Of the 25, four participants had missing data at both an item and a measure level. The highest level of missing data was from one participant, who omitted to answer any items on the CASP-19.

#### ***6.4.8 Methodological Changes for the Psychometrics Study***

Relatively minor changes were made to item wording. In the EID-Q, ‘I take part in conversations in ways that I enjoy’ was amended to ‘I enjoy conversations with others’ to improve readability. This, in addition to the removal of items that lowered the internal consistency reported earlier, led to slightly shorter measures being used in the psychometric study.

Instructions for each of the outcome measures were standardised to improve reliability across delivery. Therefore, both self-report participants and those that were interviewed had clear guidance on how to answer items within each questionnaire. Also, amendments were made to the study design with a retest being added on an optional

basis for participants, enabling the testing of measure stability. Finally, outcome measure booklets were printed one-sided as this may limit the instances of missing data.

*Table 6.7 Missing data by report style for pilot study*

Manner of Completion	Participant number	Number of missing items recorded					
		PPOM	EID-Q	CASP-19	GDS	QoL-AD	TOTAL
INTERVIEW LED	1	0	0	0	0	0	0
	2	0	0	0	0	0	0
	24	1	0	0	0	0	1
	26	0	0	0	0	0	0
	27	0	0	0	0	0	0
	29	0	0	0	0	0	0
	31	0	0	0	0	0	0
	32	0	0	0	0	0	0
SELF-REPORT	3	0	0	0	0	0	0
	4	0	0	0	0	0	0
	5	0	0	0	0	0	0
	6	0	0	0	0	0	0
	7	0	0	0	0	0	0
	8	0	0	0	0	0	0
	9	0	0	0	0	0	0
	10	0	0	0	0	0	0
	11	0	0	0	0	0	0
	12	0	0	0	0	0	0
	13	0	0	0	0	0	0
	14	0	0	0	0	0	0
	15	0	0	0	0	0	0
	16	0	0	0	0	0	0
	17	0	0	0	0	0	0
	18	0	0	0	0	0	0
	19	0	0	0	0	0	0
	20	0	0	0	0	0	0
	21	0	0	0	0	0	0
	22	0	0	0	0	0	0
	23	3	4	2	1	2	12
	25	0	0	0	0	0	0
	28	1	0	0	0	1	2
	30	5	12	19	1	1	38
	33	0	1	0	0	0	1

## 6.5 Discussion

This study entailed the pilot testing of the ‘Positive Psychology Outcome Measure’

(PPOM V2), ‘Engagement and Independence in Dementia Questionnaire’ (EID-Q V2)



and the ‘Control, Autonomy, Self-realisation and Pleasure 19’ (CASP-19). The novel outcome measures appeared easy to use, as demonstrated by the low instance of missing data in the self-report sample, thereby establishing the feasibility of using these measures by self-report in future studies.

### ***6.5.1 The Positive Psychology Outcome Measure (V2)***

Initially, the hope subscale on the PPOM V2 fell below the acceptable limit. This indicated an issue with items on this subscale as the original measure was reported as having an internal consistency of ( $\alpha = 0.78- 0.86$ ; Herth, 1992). In particular, it appeared that people with dementia struggled to answer future-oriented questions, and this is consistent with previous examinations of hope in older adults and older adults with dementia (Farran, Salloway, & Clark, 1990; Wolverson, Clarke, & Moniz-Cook, 2010) in which there appeared to be an absence of self-oriented hope for the future and hoped for goals or achievements. This issue was also evidenced in the internal consistency analysis as both future-oriented items lowered the overall internal consistency of the subscale.

Statistically significant correlations were observed between both the hope subscale and the PPOM V2 overall and the GDS, indicating a negative relationship between depression and levels of hope. The role of hope, therefore, may be that of a protective agent in the maintenance of wellbeing and consequently these people might report less depressive symptoms. This is supported by previous evidence that describes hope in dementia as being drawn on in an ongoing effort to maintain wellbeing despite the losses associated with dementia (Wolverson, Clarke, & Moniz-Cook, 2016). However, whilst a negative correlation was observed between resilience and depression, it did not reach statistical significance. This may be due to the small sample size as the literature

suggests that, like hope, resilience predicts lower depression and greater wellbeing (Lim, et al., 2015; MacLeod, Musich, Hawkins, Alsgaard, & Wicker, 2016; Smith & Hollinger-Smith, 2015). Correlations between the subscales also indicated a relationship between hope and resilience, as supported by previous research (Gooding, Hurst, Johnson, & Tarrier, 2012).

### ***6.5.2 The Engagement and Independence in Dementia Questionnaire (EID-Q)***

The first internal consistency analysis of the EID-Q demonstrated that both subscales and the overall scale had a sufficient Cronbach Alpha but, by removing two items from each subscale, the internal consistency was raised from good to excellent. However, removal of these two items led to the scale being predominantly positively worded, which had the potential to introduce response bias (Knowles & Nathan, 1997). To limit this, one negatively worded item was reintegrated for each subscale and internal consistency was found to be of an adequate level.

Preliminary convergent validity was established for the EID-Q V2 following statistically significant correlations between the GDS and the QoL-AD. Positive correlations between independence, social engagement and quality of life indicate that these factors are an important agent in the maintenance of wellbeing and protective against depressive symptoms. Indeed, the notion of independence as a predictor of wellbeing has been evidenced previously and psychosocial interventions are increasingly targeting independence for this population (e.g. Wu, Barnes, Ackerman, Lee, Chesney, & Mehling, 2015). However, in these trials, independence has previously been operationalised as merely functional, for example, the ability to feed oneself. It is proposed that independence is much more complex than this and could be more accurately described as a ‘sense of independence’ or a person’s subjective opinion of

their own level of independence. This takes into account that people may have varying levels of desired independence and is reflected in this outcome measure. It is, therefore, too simple to suggest that people with high levels of independence have a greater reported quality of life but rather that higher reported quality of life may indicate people with dementia have attained the level of independence that they are desirous of.

The inter-relatedness of social engagement and independence has been discussed previously, with the current study providing evidence for the concept of ‘interdependence’ (Woods, 1999), due to the correlation observed between the subscales on the EID-Q. This suggests that having social support may allow a person with dementia to feel independent for longer and will be examined more closely in the main trial.

### ***6.5.3 The Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19)***

Initial analysis indicated a potential issue with the CASP-19’s internal consistency. The alphas found were much lower than reported by the original authors (control:  $\alpha = .59$ , autonomy:  $\alpha = .65$ , pleasure  $\alpha = .74$  and self-realisation:  $\alpha = .77$ ) (Hyde, Wiggins, Higgs, & Blane, 2003). To compensate for this, correlations between the subscales were examined. Correlations were observed between the subscales but this was not to the degree that the original authors reported and will warrant further attention in the quantitative study. However, the CASP-19 demonstrated expected relationships with both depression and quality of life. This also provides evidence for the concurrent validity of the CASP-19 as it correlated well with an established measure of quality of life developed specifically for people with dementia. In particular, the control subscale correlated negatively with the GDS, indicating that people who have an external locus of control were more prone to depressive symptoms (Benassi, Sweeney, & Dufour,

1988). In addition, control was positively correlated with quality of life. Previously this relationship has been observed between locus of control and health related quality of life, in which stronger external locus of control was associated with poorer health related quality of life in both depressed and non-depressed older adults (Helvik, et al., 2016). The current study suggests that this relationship might extend to quality of life in general also.

#### ***6.5.4 Methodological Problems and Limitations***

Whilst it is noted that it takes on average a minimum of thirty participants or greater to estimate a parameter in a reliability pilot study (Browne, 1995), the main limitation for this study is the small sample size. This increases the risk of a type II error or failing to reject the null hypothesis. Therefore, results in the current study were interpreted with caution until further analysis in the psychometric study was completed.

Negative skews were observed on both the EID-Q V2 and the PPOM V2, indicating there is the potential for ceiling effects. However, a large proportion of the participants in this study had been attending CST groups, an intervention with a substantial evidence base for improving not only cognition but also quality of life, independent of medication taken for dementia (Acetylcholinesterase Inhibitors) (Aquirre, et al., 2013). It is, therefore, reasonable to suggest that the sample may not have been representative of people of dementia in general, as people who attend CST and similar group based sessions are potentially more socially oriented and may be more likely to engage in evidence based services. Furthermore, CST attendees are more likely to be in the milder stage of dementia and this may have impacted upon results. Therefore, efforts were made to recruit people with dementia from more avenues in the psychometrics study to

ensure that people in the study were representative of people with dementia in general, and not just those actively engaged in group based interventions.

Also, the majority completed the study by self-report and some were unaware of the specific diagnosis they had been given. In most instances, a carer was able to provide this information but there were some cases where this was not possible. In the psychometrics study, primary clinicians were contacted or medical records were accessed to provide the exact diagnosis participants were given.

The analysis of the CASP-19 was more problematic than anticipated. The CASP-19 has two future-oriented items. Feedback from participants indicated that these items were difficult to answer and this is supported from findings on the PPOM V2 that future-oriented hope was not a pertinent concept for people with dementia. This warrants further attention and slight changes may be needed to ensure that the measure has an adequate level of content validity for people with dementia. However, the original psychometric analysis was conducted in a significantly larger sample and, consequently, further examination in the psychometric study was necessary before any firm conclusions could be drawn.

#### **6.5.5 Conclusion**

Preliminary psychometric data were established for both the PPOM V2 and the EID-Q V2, hereafter which will be referred to as PPOM V3 and EID-Q V3 in recognition of the adaptations following the results of this study (Appendix 1.5 - 1.6). Both measures, alongside the CASP-19, were then subject to the larger scale psychometrics study to further establish them as robust measures.

## **7. Psychometric properties of the PPOM, EID-Q and CASP-19**

### **7.1 Introduction**

The Positive Psychology Outcome Measure (PPOM) and Engagement and Independence in Dementia Questionnaire (EID-Q) were developed using procedures outlined in Chapter 4 and 5 and piloted in Chapter 6, alongside the Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19) as part of a validation study. Due to the minor nature of amendments made to the measures in the pilot stage, data from the pilot were integrated with additional data derived from the ‘Positive Psychology Outcome Measures for People with Dementia’ (PPOM) study. The inclusion and exclusion criteria remained the same (see Chapter 6, section 6.2) and data collection procedures for PPOM followed those outlined in Chapter 6 (section 6.3 – 6.5). Outcome measures also remained the same (section 6.6). However, in this Chapter the PPOM and EID-Q shall be referred to as version 3 (V3), to reflect the minor changes made following the completion of the pilot study.

Psychometric analyses allow measures to be established as robust and the degree to which researchers undertake different analyses are variable (Allen & Yen, 1979). Analyses include that of internal consistency, test-retest reliability and convergent validity to ensure that the measure is an accurate representation of the concept it proposes to measure.

## 7.2 Aims

The aim of this chapter was to conduct a more in-depth appraisal of the psychometric properties of novel measures in a large-scale study ( $n=216$ ). Therefore, psychometric appraisals of properties were conducted for each of the measures and aims were to:

1. Describe the demographic and clinical characteristics of participants and explore whether demographics differed, based on completion style, in order to further evidence the measure's usability as self-complete or interview led.
2. Assess whether measures followed a normal distribution and whether floor and ceiling effects for measures were significant.
3. Determine whether all measures had an adequate level of internal consistency.
4. Assess whether measures were moderately stable within a one-week period.
5. Evaluate whether positive measures were related to additional measures in a manner that was theoretically expected.

## 7.3 Methods

### 7.3.1 Design

Following necessary amendments from the pilot stage, the main data collection started. This was a multisite, observational study supported by the National Institute for Health Research. Participants completed a baseline and a retest, within one week of the baseline. The order of outcome measures was randomised for each site to prevent order effects and instructions were standardised to ensure reliability across delivery. Therefore, both self-report participants and those that were interviewed were provided with clear guidance on how to answer items within each questionnaire. Retest data was

collected at North East London NHS Foundation Trust (NELFT) primarily and other sites at a later date.

### ***7.3.2 Ethics Amendments***

Two substantial amendments were submitted to the East of England – Essex Research Ethics Committee (REC) for PPOM. The first incorporated changes made to the novel measures following the psychometric analysis in the pilot stage. Also, the additional NHS sites were recruited at this stage. Approval for this amendment was received on 14<sup>th</sup> June 2016 (Appendix 3.6). A second substantial amendment was made in December 2016 to increase the sample size from 195 to 233. At this stage, the design was changed so that the ‘retest’ was no longer optional and participants would complete one baseline and one retest. Approval for this amendment was granted on 20<sup>th</sup> January 2017 (Appendix 3.7).

### ***7.3.3 Power and Sample Size***

A sample size was estimated based on the number of participants needed for a Pearson’s R correlation between the novel measures and measures selected to assess convergent validity. Power was set at 0.8, with a significance level of 0.05 and a medium effect size. Computed through G\* Power (Faul, Erdfelder, Buchner, & Lang, 2009) an estimated sample of  $n = 155$  was calculated for the main data collection stage. To assess the stability of measures, an average of 50 participants was needed to estimate substantial agreement (Atkinson & Nevill, 2000). Therefore, due to data collection issues, the sample size was increased to 230. To adequately assess the factor structure of the novel measures, a sample size of the number of items within a measure multiplied by seven was recommended as being needed (Terwee, et al., 2007). The largest measure (EID-Q) was 26 items and, therefore, the minimum sample size needed was 182.



#### **7.3.4 Recruitment**

Following completion of the pilot stage, PPOM was given support by the National Institute for Health Research (NIHR) and adopted as a portfolio study. Additional sites were also recruited to maximise variability within the sample. In addition to NELFT, the study was approved at Nottinghamshire Healthcare NHS Foundation Trust, Black Country Partnership NHS Foundation Trust, Humber NHS Foundation Trust and Derbyshire Healthcare NHS Foundation Trust. Additional sites were approved on 30<sup>th</sup> June 2016 and a 'Schedule of Events' and 'Site Specific Activities' were approved by the relevant professional within each NHS site (Appendix 3.4). Participants within NHS sites were identified through previous research, the Join Dementia Research (JDR) website and memory clinic attendance. Each NHS site was responsible for recruiting, screening and completing the study with participants within their site and were required to follow guidance in the research protocol. Recruitment began in April 2016 and ended in May 2017.

#### **7.3.5 Retest Procedure**

Retest data was collected at NELFT primarily and Humber NHS and Black Country Partnership NHS at a later date. Originally, the retest was on an optional basis for participants. However, due to retest data only being collected at NELFT, accruals were approaching the maximum sample size of 195 and only a small subset of participants had been retested. Therefore, the aforementioned second substantial amendment was submitted to increase the sample size to 233 and amend the design of the study so that retesting was no longer optional for participants. Furthermore, Humber and Black Country NHS agreed to collect retest data within their respective sites. Participants were asked to complete the study again, following a period of one week. Screening, consent

and data collection procedures outlined in Chapter 6 (sections 6.4 – 6.5) were followed and the manner of completion did not differ between test and retest. Consent was treated as an on-going process and re-affirmation of willingness to participate was sought at baseline and retest. If a participant declined to complete the retest section of the study, this was respected.

### ***7.3.6. Source Data Validation***

As data were input onto an Excel spreadsheet at sites by NHS staff and transferred to the Statistical Package for the Social Sciences (SPSS) by the primary researcher, a random selection from SPSS was screened against hard copies. 10% of completed assessment packs were selected using a random number generator. For each NHS site, if incorrect data had been entered, this was corrected. For each site, if more than ten items had incorrect data across all participants from that site, all hard copies were screened against SPSS for that particular NHS site. If a participant within this 10% was part of the retest sample, both baseline and retest was screened against SPSS for incorrect data. There were very minor instances of incorrectly entered data in the 22 hard copies that were screened. Only two participants had incorrect data entered, with one item on the QoL-AD being entered incorrectly for one and one item on the CASP-19 being entered incorrectly for the second.

### ***7.3.7. Missing Data***

Missing data strategies have implications for psychometric appraisals, with high levels of missing data impacting upon conclusions that can be drawn. Missing data can be defined as missing completely at random (MCAR), missing at random (MAR) and missing not at random (MNAR) (Schafer, 1997). However, MCAR is rare in surveys where the sample size is moderately large (Garson, 2015). There are seven recognised

methods for dealing with missing data including listwise and pairwise deletion and multiple imputation.

Multiple imputation replaces missing data with a set of plausible alternatives. In this way, multiple imputation reflects the uncertainty about which values are the right ones to impute (Rubin, 1987) and is recommended when MCAR assumptions are violated (Graham, 2009). It is also now seen as the gold standard against which newer methods are compared (van Buuren, 2012).

Previously, between three to five imputations was considered acceptable (Rubin, 1996) but recently there have been calls for increased imputations such as using 40 imputations for data with a missing value rate of 50% (Graham, Olchowski, & Gilreath, 2007).

On a value-by-value basis, 99.3% were completed with only 0.7% representing incomplete values at baseline. Furthermore, missing data for each measure was low. The PPOM V3 was completed in 92.6% of cases, the EID-Q V3 was completed in 91.7% of cases, the CASP-19 was completed in 93.5% of cases, the QoL-AD was completed in 93.1% of cases and the GDS was completed in 90.7% of cases. To explore whether the data in this study was MCAR, MAR or MNAR, a series of steps were undertaken, which determined which method of dealing with missing data would be most appropriate. Firstly, using Estimation Maximisation Likelihood, a Little's MCAR test was undertaken for all cases in the baseline assessment. The test was significant ( $p < .001$ ) indicating that data was not MCAR. However, results indicated that no variables had 5% or more missing values limiting the ability to ascertain whether data was MNAR or MAR. A missing value analysis indicated that 78.7% of participants had

complete data. Removing participants on a listwise basis would entail removing 46 participants from the sample, leaving an overall sample of 170 to analyse. By reducing the rate of missing values to 1% in the missing values analysis, a series of independent t-tests could be conducted, indicating that items, to some degree, could predict other items. This is consistent with MAR and therefore, a combination of mean and multiple imputation was the most appropriate means of dealing with missing data.

Previous studies using the CASP-19 suggested imputing data at the 10% level (Kim, et al., 2015). This was done for the CASP-19, PPOM V3, EID-Q V3 and the GDS.

Authors of the QoL-AD suggest that if more than two items are considered missing, the whole measure should be considered missing. These rules for missing data are considered part of a validated tool and, consequently, data for the QoL-AD was imputed at 20%. As there was a low level of missing data in the current study, 20 imputations were requested for each summary score.

Post-imputation, variable completion by cases improved significantly. Completed cases represented 95.8% of the data ( $n = 207$ ), with only 9 cases noted as incomplete. On a value-by-value basis, completed values represented 99.7% of the data.

For the subsample of participants who took part in the retest, 75% represented complete cases and 96.2% had completed values. A Little's MCAR test indicated that results were not significant ( $p = 1.000$ ) suggesting that data was MCAR. As missing data was minimal, mean imputation was used at the same levels as described previously and summary scores were calculated using multiple imputation procedures. Post imputation, completed cases represented 77.5% of data and 96.8% represented completed values.

### **7.3.8 Detecting Outliers**

Similar to missing data, outliers have implications for psychometric appraisals. Outliers refer to data that falls outside of the normal distribution by two standard deviations (Fields, 2009). A z-test is then performed to examine whether outliers fall outside of the normal distribution. The formula for a z-test is given as:  $Z_i = \frac{Y_i - \bar{Y}}{s}$ . Outliers help to determine whether a measure follows a normal distribution.

In the PPOM V3, three cases were identified as outliers, lying outside of two standard deviations from the mean. However, two of these participants had been diagnosed with depression, whilst the one remaining case scored high on the GDS, indicating depression. As the relationship between positive concepts and depression was explored later in this thesis, these outliers were retained for future analysis. Two outliers were identified for the EID-Q V3, one of which was the same participant identified as an outlier on the PPOM V3, who had been diagnosed with depression. The second outlier for the EID-Q V3 again had a z-score that fell two standard deviations below the mean. However, again this participant had been diagnosed with depression and was retained for further analysis. A visual inspection of a boxplot for the CASP-19 again identified the same case as a potential outlier. A second case also fell below two standard deviations from the mean and, again, this person scored highly on the GDS so was retained.

### **7.3.9 Data Normality and Distribution**

Normally distributed data is characterised by a bell curve that is symmetrical, with the greatest frequency of scores in the middle and lower frequencies of data toward the ends. Skewness and kurtosis indicate departures from normality with skewness referring

to larger amounts of data falling toward one end of a bell curve, rather than the middle and kurtosis refers to the peakedness of a distribution. Where too much data falls in the middle of a distribution, it indicates a peaked distribution and where data falls more toward the extremes, it indicates a flat distribution. When the skew value is close to '0', this implies symmetric distribution (Hae-Young, 2013). Histograms with a distribution curve are recommended as a visual aid to determine normality (Allen & Yen, 1979). However, larger sample sizes are known to impact upon levels of skew and kurtosis (Joanes & Gill, 1998) and that, in large samples, normality is less concerning. Furthermore, transforming data because of a non-normal distribution presents problems with interpretability and is not universally recommended (Fields, 2009).

Visual inspection of histograms indicated that there were moderately negative skews on the PPOM V3 (-.891), CASP-19 (-.656) and EID-Q V3 (-.774). The PPOM V3 was slightly leptokurtic (.526), whilst both the CASP-19 and EID-Q V3 were more normal (.062 and .132 respectively). Whilst this indicates that data for the current study may not have been normally distributed, parametric tests were used as, in larger sample sizes, skew and kurtosis do not make a substantive difference in analysis (Tabachnick & Fidell, 1996).

### **7.3.10 Data Analysis**

#### *7.3.10.1 Participant demographics and clinical variables*

Frequency, percentages and ranges were examined for all demographic information including age, gender, dementia sub-type diagnosis, ethnicity and marital status.

Participants were also examined for the amount of time spent living with dementia.

Proportions of participants also taking anti-dementia medication, additional psychotropic medication and co-morbid conditions were examined.

Following this, self-completers and interview led completers were examined for significant differences on all demographic and clinical characteristics. An independent samples t-test was conducted to determine whether self-completers were significantly different in terms of the above characteristics to those who were interviewed.

Furthermore, average scores on all outcome measures in the study were compared to assess significant differences for completing style.

#### *7.3.10.2 Floor and ceiling effects*

Measure norms for the PPOM V3, EID-Q V3 and CASP-19 were taken using means, medians, standard deviations, range and possible ranges. To assess floor and ceiling effects, the number of participants who achieved the highest or lowest possible scores were examined. If less than 15% of respondents achieved the highest or lowest possible scores, ceiling and floor effects were not considered significant (Terwee, et al., 2007).

#### *7.3.10.3 Internal consistency*

The PPOM V3 was subject to a Cronbach Alpha test to ascertain levels of internal consistency. Both subscales were analysed, as the scale consists of two concepts: hope and resilience. As with the PPOM V3, the EID-Q V3 was subject to an internal consistency analysis. Both subscales: independence and engagement were hypothesised to have an adequate internal consistency, as was the EID-Q V3 overall. Acceptable internal consistency has a range of  $0.9 > \alpha \geq 0.7$  (George & Mallery, 2003). Internal consistency was analysed following completion of the pilot stage and redundant items were removed before data collection recommenced. The CASP-19 was subject to an internal consistency analysis. The original authors reported alphas for each subscale, some of which one of which fell below the acceptable limit but did not report the

overall alpha. Alphas reported by the original authors were:  $\alpha = .59$  (control),  $\alpha = .65$  (autonomy),  $\alpha = .74$  (pleasure) and  $\alpha = .77$  (self-realisation). This analysis was supplemented by a correlation coefficient analysis between subscales that indicated a high degree of inter-relatedness between domains. This analysis was undertaken for the present study. To analyse whether domains on subscales for each measure were related, a Pearson's R correlation was calculated between subscales and total measure scores.

#### *7.3.10.4 Test-retest reliability*

Test-retest reliability is used to assess measure stability over time in stable participants and is subject to two conditions. Firstly, that the true score does not differ between test and retest and, secondly, that the time period between test and retest is long enough to prevent learning or recall. However, this time period should reflect an understanding of the concept to be measured and the characteristics of participants (Vaz, Falkmer, Passmore, Parsons, & Andreou, 2013). Perfect scores between test and retest (e.g. 1) are rare, as all measures are subject to measurement error. However, test-retest reliability assumes that, with any concept, there is an observed score that is comprised of the true score plus error (Portney & Watkins, 2000). As short-term memory loss is a predominant feature of dementia, it was assumed that a one-week period between test and retest would be sufficient to ensure that learning effects did not take place.

Furthermore, the characteristics assessed by both the PPOM V3 and the EID-Q V3 may fluctuate over time and be influenced by external and uncontrollable life events such as illness or financial trouble. It was therefore also assumed that, whilst there would be a moderate level of agreement between test and retest, agreement would not be perfect.

Data collected from the subsample of participants who completed the measures twice, were analysed using an Intraclass Correlation Coefficient (ICC) in a one-way random



effects model and 95% confidence intervals (CI) (Rankin & Stokes, 1998; Shrout & Fleiss, 1979). ICCs were selected in place of Pearson's R as ICCs measure the strengths of agreement, rather than a linear relationship making them preferable for an analysis of test-retest reliability (Allen & Yen, 1979).

To assess stability of the participants in the retest subsample, established measures were examined first for stability. The QoL-AD has previously been established as remaining moderately stable over a one-week interval, with reported ICCs ranging from .76 (Logsdon, Gibbons, McCurry, & Teri, 1999) in a sample of 30 people with dementia and .6 in a sample of 38 people with dementia (Thorgrimsen, et al., 2003). If agreement on the QoL-AD was above 0.6, participants were considered to have remained stable over the one-week period. The GDS has not been subject to an assessment of test-retest reliability for people with dementia but has been found to be stable in older adult populations with ICCs over a two-week period being calculated as .83 (Nyunt, Fones, Niti, & Ng, 2009) and a Pearson's R calculated as 0.75 in post-stroke older adults (Sivrioglu, et al., 2009). Therefore, participants were considered stable when scores on the GDS were .8 and above (see section 7.4.1.1, subsample characteristics for an assessment of stability for the QoL-AD and GDS). Following an assessment of the stability of the established measures, the PPOM V3, EID-Q V3 and CASP-19 were subject to an ICC to assess whether each measure remained stable within a one-week period. As a perfect linear agreement (+1) is unlikely, magnitude guidelines were adopted. Agreement was considered poor if below 0.5, moderate if between 0.5 and 0.75, good if between 0.75 and 0.9 and excellent if above 0.9 (Portney & Watkins, 2000). It was hypothesised that measures would remain relatively stable at retest, with an ICC of between 0.5 and 0.75 indicating reliability. Furthermore, scatter plots were

requested using SPSS to provide a visual representation of the relationship between test and retest for all measures.

#### *7.3.10.5 Convergent validity*

A Pearson Product-Moment Correlation Coefficient (Pearson's R) is a measure of the linear correlation between two variables, giving a value between +1 and -1, where 1 is a total positive correlation, 0 is no correlation and -1 is a total negative correlation (Faul, Erdfelder, Buchner, & Lang, 2009). A Pearson's R analysis was selected over an Intraclass Correlation Coefficient (ICC) as Pearson's R measures a linear relationship rather than agreement between ratings. Pearson's R was calculated between the PPOM V3, EID-Q V3, CASP-19 V3 and the QoL-AD and GDS, providing an indication of whether positive psychology scales were related to quality of life and depression. Furthermore, cut off points were used to assess the relationship between participants that were very likely to have depression, as scored by the GDS, and those that reported no depressive symptoms. Those that scored 10 or greater on the GDS were compared with those that scored less than 5 via an independent samples t-test for totals on the PPOM V3, EID-Q V3 and CASP-19.

## **7.4 Results**

### ***7.4.1 Participant demographics and clinical variables***

Participants consisted of 123 men and 93 women (n = 216) with an average age of 77.5 years (Table 7.1). Participants were predominantly married individuals (65.3%), residing within the community (97.2%). Only 17 participants came from Black and Minority Ethnic (BME) groups, with the vast majority indicating they were White British (91.4%).

*Table 7.1 Participant demographics for psychometric study*

	Total Sample (n =216)	Subsample (n =40)
Gender <i>n</i> (%)		
Male	123 (56.9)	23 (57.5)
Age <i>M</i> ( <i>SD</i> ) Range	77.5 (9.24) 53-99	77.7 (10.37) 59-99
Marital status <i>n</i> (%)		
Single	8 (3.7)	4 (10)
Married	141 (65.3)	25 (62.5)
Widowed	50 (23.1)	8 (20)
Divorced	13 (6)	2 (5)
Other	4 (1.9)	1 (2.5)
Residing <i>n</i> (%)		
Community	210 (97.2)	39 (97.5)
Residential Facility	6 (2.8)	1 (2.5)
Trust recruited from <i>n</i> (%)		
North East London	39 (18.1)	16 (40)
Black Country Partnership	69 (31.9)	16 (40)
Humber Partnership	40 (18.5)	7 (17.5)
Nottingham	25 (11.6)	0 (0)
Derbyshire	20 (9.3)	0 (0)
Voluntary Organisation	23 (10.6)	1 (2.5)
Ethnicity <i>n</i> (%)		
White (British)	192 (88.9)	36 (90)
White (other)	10 (4.9)	3 (7.5)
Black	4 (1.9)	1 (2.5)
Asian	3 (1.5)	0 (0)
Unknown (missing)	6 (2.8)	0 (0)

Clinically, most participants had been diagnosed with Alzheimer's disease (48.1%) or mixed dementia (21.3%). Other dementias identified were dementia due to Parkinson's disease (0.9%), Frontotemporal dementia (2.3%) and Primary Progressive Aphasia (0.9%). Seventeen participants did not disclose the subtype of dementia they had been diagnosed with. Reasons for non-disclosure were variable with some participants

indicating that they had not been informed as to the specific type, could not remember the sub-type and information being unavailable at respective research sites (Table 7.2).

*Table 7.2 Participant clinical characteristics for psychometric study*

	Total Sample (n = 216)	Subsample (n =40)
Dementia diagnosis <i>n</i> (%)		
Alzheimer's disease	104 (48.1)	21 (52.5)
Vascular dementia	40 (18.5)	8 (20)
Dementia of mixed aetiology	46 (21.3)	7 (17.5)
Parkinson's related dementia	2 (0.9)	1 (2.5)
Frontotemporal dementia	5 (2.3)	2 (5)
Primary Progressive Aphasia	2 (0.9)	0 (0)
Dementia due to cardiovascular disease	1 (0.5)	0 (0)
Dementia (sub-type unknown)	16 (7.4)	1 (2.5)
Time since diagnosis <i>n</i> (%)		
<1 year	72 (33.3)	17 (42.5)
1- 2 years	50 (23.1)	7 (17.5)
2- 3 years	37 (17.1)	7 (17.5)
3> 4 years	22 (10.2)	2 (5)
> 4 years	18 (8.3)	5 (12.5)
Unknown	17 (7.9)	2 (5)
Acetylcholinesterase inhibitor <i>n</i> (%)		
None	85 (39.4)	15 (37.5)
Donepezil	87 (40.3)	15 (37.5)
Other	44 (20.4)	10 (25)
Other major mental or physical health problem <i>n</i> (%)		
None	162 (75)	30 (75)
Depression	16 (7.41)	2 (5)
Anxiety	6 (2.8)	2 (5)
Other	32 (14.8)	6 (15)
Other medication <i>n</i> (%)		
None	178 (82.4)	34 (85)
Antidepressant	25 (11.6)	4 (10)
Antianxiety	4 (1.9)	1 (2.5)
Other	9 (4.2)	0 (0)

All demographic and clinical characteristics of participants were examined for significant differences according to completion style of which two emerged as having an impact. Firstly, age emerged as potentially different with younger participants more likely to complete the study in a self-report fashion ( $M = 75.72$ ,  $SD = 8.91$ ) than their older counterparts ( $M = 78.58$ ,  $SD = 9.33$ ) ( $t(214) = -2.23$ ,  $p = .025$ ). Finally, years post diagnosis emerged as potentially significant as people in the self-report sample were more likely to have spent longer living with their diagnosis ( $M = 1.97$ ,  $SD = 1.72$ ) than the interview led sample ( $M = 1.37$ ,  $SD = 1.479$ ) ( $t(162.96) = 2.635$ ,  $p = .009$ ).

Average scores did not differ by completion style for the PPOM V3 ( $t(21273144) = -1.519$ ,  $p = .129$ ), the CASP-19 ( $t(2635519) = .279$ ,  $p = .780$ ), the EID-Q V3 ( $t(47240405) = -.194$ ,  $p = .847$ ), the GDS ( $t(385170) = .299$ ,  $p = .765$ ) and the QoL-AD ( $t(11727975) = .035$ ,  $p = .972$ ) indicating that the measures can be successfully used as either self-report or in an interview.

#### *7.4.1.1 Subsample characteristics*

The subsample of participants was largely representative of the sample in its entirety. Participants were community dwelling individuals with a largely even split between male and female (57.5% to 42.5%), and had a mean age of 77.68 years ( $SD = 10.367$ ). Over half had been diagnosed with Alzheimer's disease ( $n = 21$ ), and were almost exclusively White British (90%) (Tables 7.1 and 7.2).

To ensure the subsample of participants were representative, a series of independent samples t-tests were conducted for all demographic and clinical information. No

characteristics were significant, indicating that the subsample was an accurate representation of the sample in full.

To assess the stability of participants between test and retest, the QoL-AD and GDS were examined for consistency between assessments. The QoL-AD had an ICC of .822, with a 95% CI from .679 to .905 ( $F(35,36) = 10.208, p < .001$ ), indicating ‘good reliability’ between test and retest. A visual inspection of the scatter plot also indicated linear consistency between assessments. This provided evidence to suggest that participants remained stable within a one-week period.

The ICC for the GDS was moderate with an ICC of .653 and a 95% confidence interval of .431 to .801 ( $F(38,39) = 4.766, p < .001$ ). Whilst lower than the QoL-AD, .653 was deemed sufficient to suggest moderate stability from test-retest for participants.

Furthermore, internal consistency of the QoL-AD was identified as  $\alpha = .858$ , similar to the alpha reported by other authors, and the GDS had an internal consistency of  $\alpha = .842$  for the current study.

## **7.4.2 The PPOM V3**

### *7.4.2.1 Floor and ceiling effects*

As discussed previously, prior to imputation, the PPOM V3 had a moderately negative skew and was leptokurtic (Figure 7.1). Possible scores ranged from 0- 64 and the observed range was 6-64. The mean was 48.44 (SD = 12.2.). No participant scored the lowest possible score and 14 participants achieved the maximum possible score of 64. This represented 6.48% of the sample and therefore ceiling effects for the PPOM V3 were not considered significant. Across the 20 imputations, the distribution remained relatively unchanged, for example, for imputation four the mean was 48.42 (SD = 12.1).

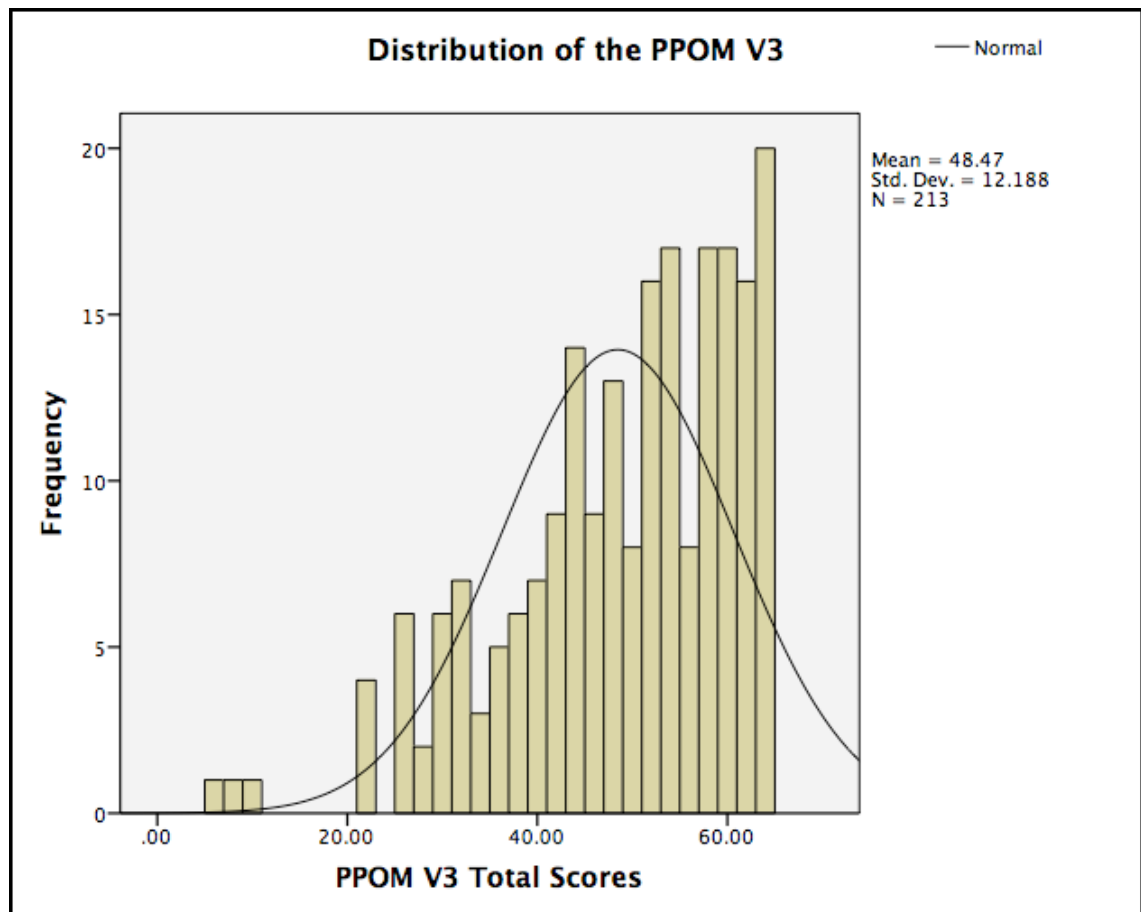


Figure 7.1 Original distribution of the PPOM V3 for psychometric study

#### 7.4.2.2 Internal consistency

A Cronbach's alpha analysis indicated that the PPOM V3 had an overall internal consistency of  $\alpha = .939$ , representing a slight increase from the pilot study in which the internal consistency was recorded as  $\alpha = .849$ . This indicated that the internal consistency had improved from 'good' to 'excellent' (George & Mallery, 2003) and was not indicative of multicollinearity ( $\alpha > .95$ ). No items were identified that would improve internal consistency if deleted, meaning the PPOM V3 had an adequate level of content validity. For the hope subscale, internal consistency was  $\alpha = .876$  and, again, no items were identified that would improve the internal consistency if removed. The resilience subscale had an internal consistency of  $\alpha = .915$  with no items identified as improving the internal consistency if deleted. Correlations between both subscales were significant, with a positive correlation observed between the hope and resilience

subscale ( $r = .788, p < .001$ ). Also, both the hope and resilience subscale were significantly correlated with the overall measure ( $r = .938, p < .001$ ;  $r = .953, p < .001$ ). These correlations indicated the relatedness of positive psychology concepts for people with dementia and provided further evidence for their combination into one measure.

#### *7.4.2.3 Test-retest reliability*

Consistency between the PPOM V3 at baseline and retest was moderate (ICC= .613), with a CI of .366 and .636 ( $F(36,37) = 4.162, p < .001$ ). The scatterplot indicated a moderate linear agreement towards the lower end of the PPOM V3, with variation between test and retest becoming larger with increased scores (Figure 7.2). However, the scatterplot identified two outliers. One participant scored very high at baseline, whilst scoring much lower at retest and one participant had a low score at baseline and high one at retest. After these cases were removed from the analysis, consistency greatly improved with an ICC value of .853 and 95% confidence intervals of .730 and .923 ( $F(34,35) = 12.634, p < .001$ ). Consequently, these anomalies were removed from the analysis. At a subscale level, consistency was good. The resilience subscale had an ICC value of .879, with a 95% CI from .776 to .937 ( $F(34,35) = 25.567, p < .001$ ) and the hope subscale was considered moderate (ICC= .745), with a 95% CI of .553 to .862 ( $F(34,35) = 6.84, p < .001$ ).



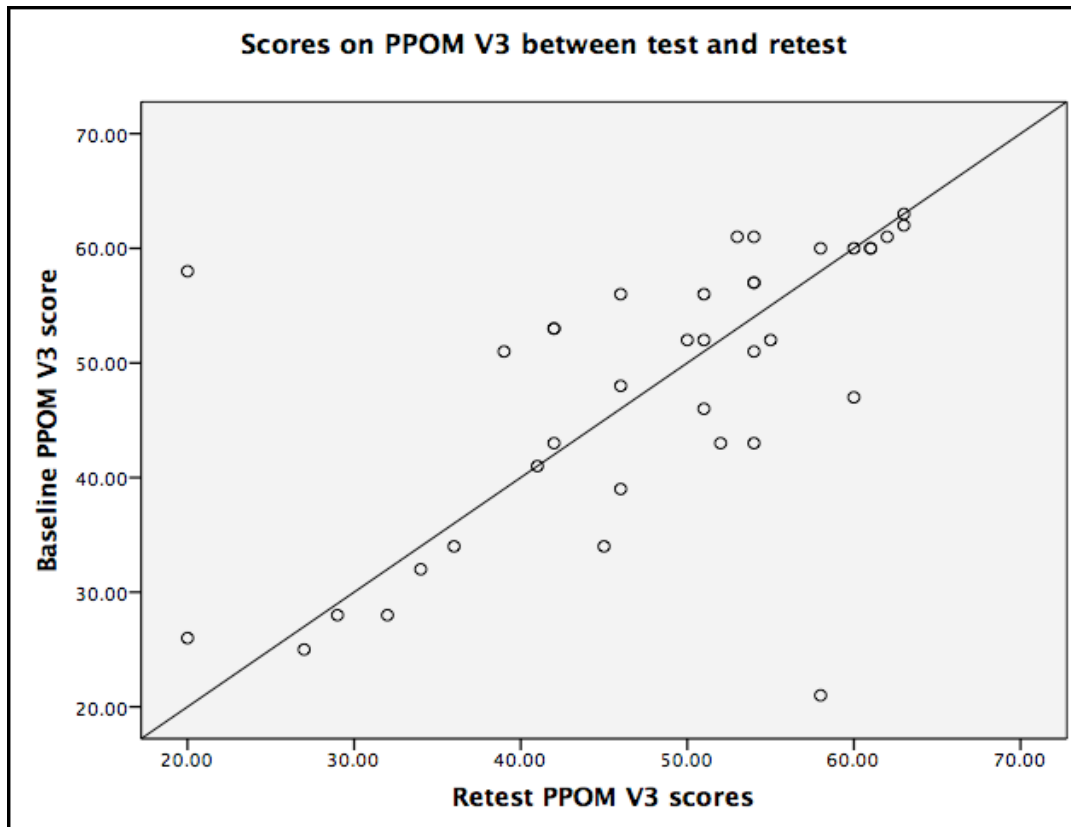


Figure 7.2 Scatter plot of the PPOM V3 between baseline and retest for psychometric study

#### 7.4.2.4 Convergent validity

Pearson's R correlations were conducted between both subscales, the measure overall and the QoL-AD. Both the hope and resilience subscales were significantly correlated with the QoL-AD ( $r = .579, p < .001$ ;  $r = .551, p < .001$ ), as was the measure total ( $r = .596, p < .001$ ). This is in contrast to the pilot study (Chapter 6) in which no significant correlations were found between these concepts and may potentially suggest the pilot study was subject to Type II error. A second Pearson's R correlation was conducted to assess the relationship of between hope, resilience and depression. A negative correlation was observed between both hope and resilience subscales ( $r = -.676, p < .001$ ;  $r = -.595, p < .001$ ) and between the GDS and PPOM V3 total ( $r = -.669, p < .001$ ).

An independent samples t-test indicated that people who scored less than five on the GDS scored significantly higher on the PPOM V3 ( $M = 53.08$   $SEM = .71459$ ) than those who scored ten or greater on the GDS ( $M = 29.17$   $SEM = 2.48$ ) ( $t(164956751) = 11.83, p < .001$ ).

### **7.4.3 The EID-Q V3**

#### *7.4.3.1 Floor and ceiling effects*

A visual inspection of the distribution of the EID-Q V3 using histograms indicated a slight negative skew (Figure 7.3). The possible range of the EID-Q was 0 - 104 with the observed range being calculated as 26 - 104. The mean score was 81 ( $SD = 16.2$ ). One participant scored the lowest recorded overall score (26), whilst six participants achieved the maximum possible score (104). This represented 2.8% of the sample and, therefore, ceiling effects were not considered to be significant. Again, post imputation, the distribution did not vary greatly. For example, the mean for imputation 9 was 81 ( $SD = 16.1$ ).

#### *7.4.3.2 Internal consistency*

Internal consistency for the EID-Q V3 was  $\alpha = .921$  and had increased from the pilot study ( $\alpha = .907$ ). Both of these alpha levels were within the ‘excellent’ range and, although increasing, did not constitute multicollinearity. The deletion of one item (‘I am often ignored by those around me’) would have improved the internal consistency but to a negligible amount ( $\alpha = .923$ ). The sense of independence subscale had an internal consistency of  $\alpha = .899$  and no items were identified as improving the internal consistency when removed. The social engagement subscale had an internal consistency of  $\alpha = .840$ . The aforementioned item that would improve the internal consistency of the overall measure was identified again in the subscale analysis as improving the internal

consistency when removed but, again, this was by a negligible amount ( $\alpha = .848$ ). Both subscales on the EID-Q V3 were significantly correlated with each other and with the measure overall. Firstly, a positive correlation was observed between the sense of independence subscale and social engagement subscale ( $r = .740, p < .001$ ) and secondly, both subscales were observed to be positively correlated with the measure in its entirety ( $r = .949, p < .001$ ;  $r = .914, p < .001$ ). This provided evidence to the inter-relatedness of independence and social engagement discussed in Chapter 5.

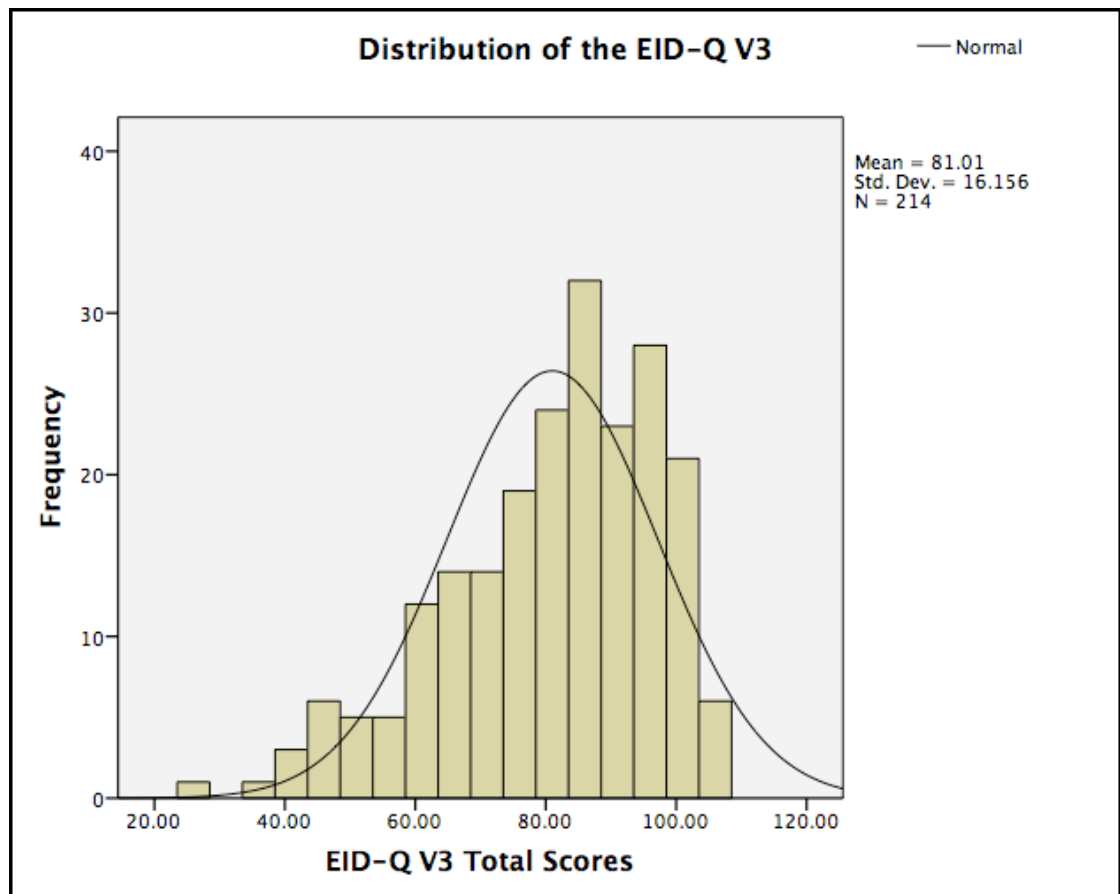


Figure 7.3 Original distribution of the EID-Q V3 for psychometric study

#### 7.4.3.3 Test-retest reliability

The EID-Q V3 remained moderately stable at retest (ICC= .725), with 95% CI of .529 to .848 ( $F(36,37) = 6.267, p < .001$ ). A visual inspection of the scatter plot indicated that there was linear consistency between baseline and retest. Scores were distributed around the higher levels of the EID-Q with two potential outliers being identified (Figure 7.4).

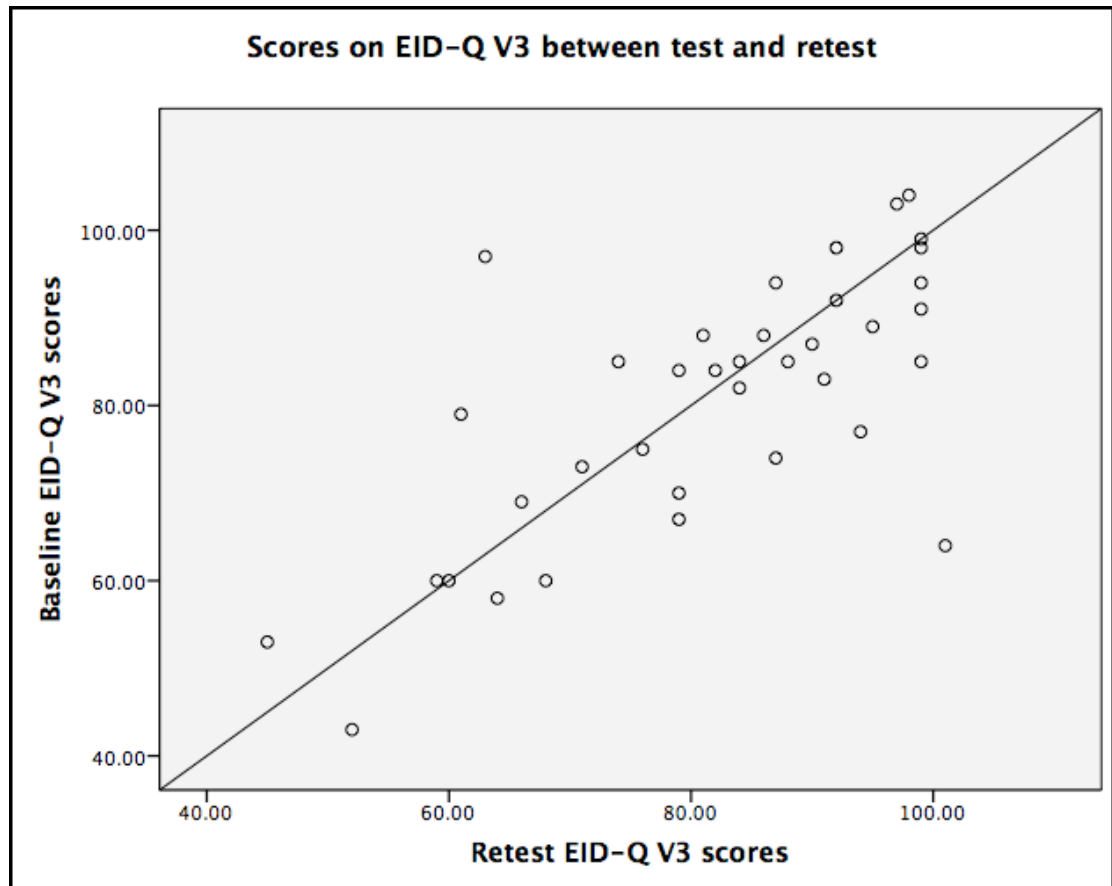


Figure 7.4 Scatter plot of scores on EID-Q V3 between baseline and retest for psychometric study

However, these outliers were not as substantial as those identified in the PPOM V3 analysis and so were retained. At a subscale level, sense of independence showed moderate consistency (ICC= .687), with a 95% CI of .473 to .825 ( $F(36,37) = 5.390, p < .001$ ) and social engagement also showed moderate consistency (ICC= .715), with a 95% CI of .514 to .842 ( $F(36,37) = 6.019, p < .001$ ).

#### 7.4.3.4 Convergent validity

Pearson's R correlations were conducted between subscales of the EID-Q and both the QoL-AD and GDS. A significant, positive correlation was identified between the sense of independence subscale and the QoL-AD ( $r = .653, p < .001$ ) and the social engagement subscale and the QoL-AD ( $r = .663, p < .001$ ). A significant correlation was also observed for the EID-Q V3 overall and total scores on the QoL-AD ( $r = .704, p$

<.001), evidencing the EID-Q V3's convergent validity with quality of life. Negative correlations were observed between the GDS and the EID-Q V3. The sense of independence subscale was negatively correlated ( $r = -.654, p < .001$ ) as was the social engagement subscale ( $r = -.638, p < .001$ ). Finally, the overall scores for both measures were negatively correlated ( $r = -.693, p < .001$ ). All correlations were moderate indicating that, whilst related, the EID-Q, QoL-AD and GDS were measuring different concepts.

An independent samples t-test indicated that people who scored less than five on the GDS scored significantly higher on the EID-Q V3 ( $M = 87.34$   $SEM = .965$ ) than those who scored ten or greater on the GDS ( $M = 57.04$   $SEM = 3.09$ ) ( $t(196454029) = 11.311, p < .001$ ). This indicated that participants who were more likely to have substantial depressive symptoms were more likely to feel less independent and socially engaged than those who did not report depressive symptomology.

#### **7.4.4 The CASP-19**

##### *7.4.4.1 Floor and ceiling effects*

A visual inspection of the histogram suggested that the CASP-19 followed a relatively normal distribution, with a very slight negative skew (Figure 7.5). Post imputation, the possible range of the CASP-19 was 0- 57 and the observed range for the current study was 15-57. Mean scores were 40.8 ( $SD = 8.9$ ). No participant scored zero, whilst two participants achieved the highest possible score of 57, indicating that floor and ceiling effects were not significant. Imputations did not greatly affect the distribution of the CASP-19. The mean for imputation 17 was 40.8 ( $SD = 8.8$ )

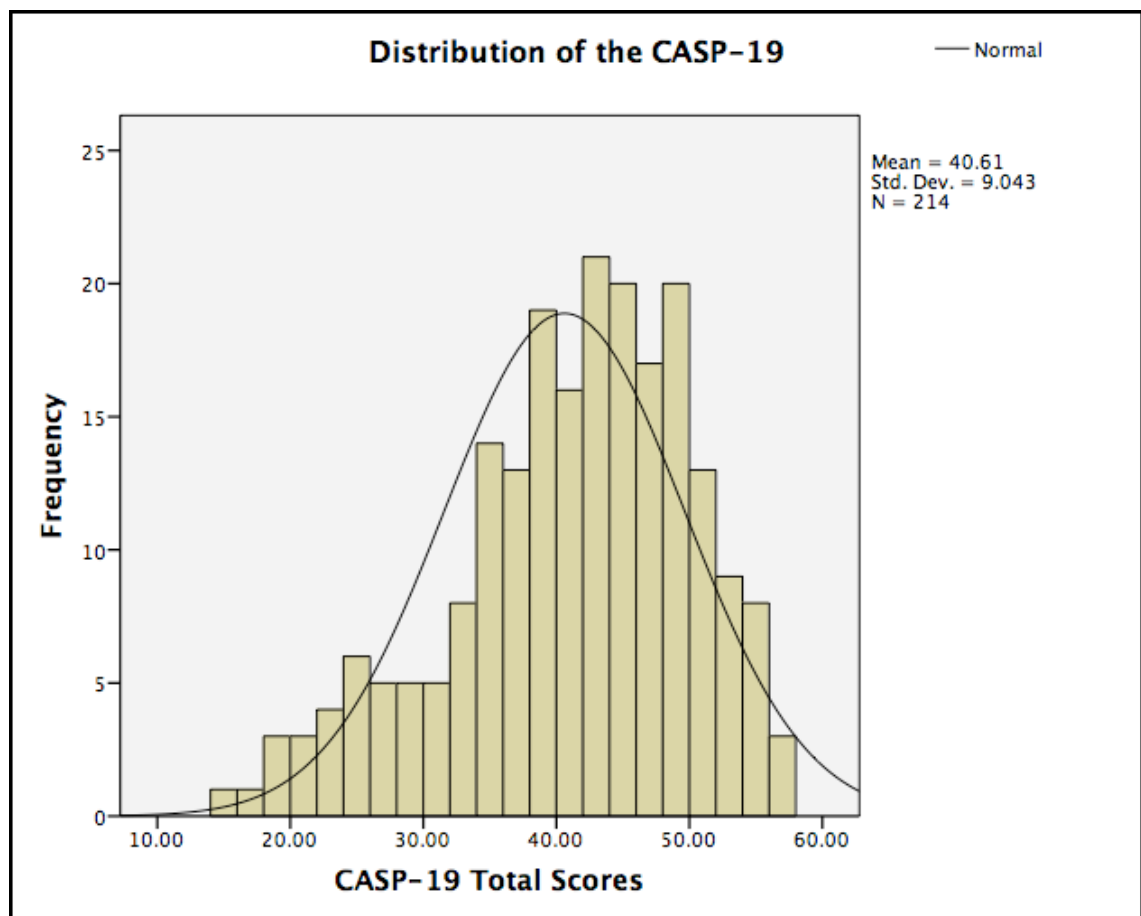


Figure 7.5 Original distribution of the CASP-19 for psychometric study

#### 7.4.4.2 Internal consistency

The internal consistency of the CASP-19 was  $\alpha = .851$ , representing a substantial increase from the pilot study ( $\alpha = .678$ ). Two items were identified as improving the alpha if removed ('family responsibilities prevent me from doing what I want to do' and 'shortage of money stops me from doing the things I want to do'), suggesting these items may not be as relevant for people with dementia as they were for older adults. The family responsibilities item was also identified as improving the consistency if removed at the subscale level. However, removing these items would only improve the consistency minimally ( $\alpha = .854$  and  $\alpha = .859$  respectively) and therefore they were retained. As the original authors of the measure did not conduct an internal consistency

for the measure in its entirety, it was not possible to compare the alphas across studies. However, the authors reported alphas for each of the subscales and these were compared to the current study. Firstly, the control subscale alpha was  $\alpha = .634$ , which represented an improvement from the original alpha of  $\alpha = .59$ . Secondly, the autonomy subscale had an alpha of  $\alpha = .504$  which was not as high as the original of  $\alpha = .65$ . Thirdly, the pleasure subscale was  $\alpha = .718$  and this was very similar to the originally reported alpha of  $\alpha = .74$ . Finally, the self-realisation subscale had an internal consistency of  $\alpha = .783$ , which again was very similar to the original of  $\alpha = .77$ . This indicated that whilst internal consistency was adequate at a measure level, the autonomy subscale fell below the acceptable limit, suggesting this particular subscale holds less validity for older adults with dementia. As within the pilot and to provide evidence for a similar factor structure, a Pearson's R correlation was conducted between subscales (Table 7.3).

*Table 7.3 Correlation coefficients of the CASP-19 in psychometric study*

	<b>Control</b>	<b>Autonomy</b>	<b>Self-realisation</b>	<b>Pleasure</b>
<b>Control</b>	1			
<b>Autonomy</b>	.567	1		
<b>Self-realisation</b>	.461	.468	1	
<b>Pleasure</b>	.244	.362	.380	1

*all significant at .001 level (2-tailed).*

Whilst correlations had improved from the pilot study and were all significant to the  $p < .001$  level, correlations were less than observed in the original study of older adults without dementia (see Chapter 6, Table 6.13).

#### 7.4.4.3 Test-retest reliability

The CASP-19 showed good consistency within a one-week period ( $ICC=.817$ ), with a 95% CI of .674 to .901 ( $F(36,37) = 9.923, p < .001$ ). No significant outliers were observed on the scatter plot (Figure 7.6). The control subscale demonstrated moderate consistency ( $ICC= .616$ ) with 95% CI of .378 to .778 ( $F(38,39) = 4.202, p < .001$ ) as did the autonomy subscale ( $ICC= .694$ ; 95% CI= .490 - .827) ( $F(38,39) = 5.546, p < .001$ ).

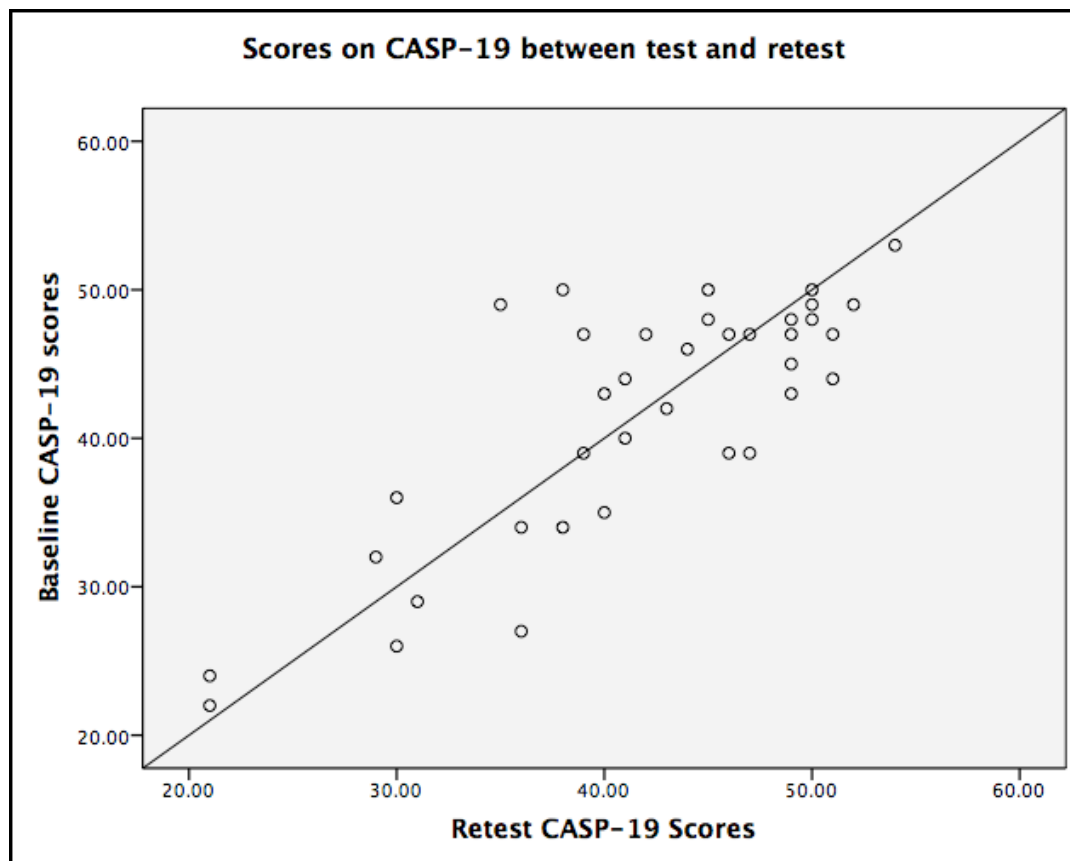


Figure 7.6 Scatter plot of scores on CASP-19 between test and retest for psychometric study

The pleasure subscale also demonstrated moderate consistency, although this was lower than both the autonomy and control subscales ( $ICC= .506$ , 95% CI= .224 – .710) ( $F(36,37) = 3.047, p = .001$ ).



A visual inspection of a scatter plot indicated that consistency for this particular subscale was weak (Figure 7.7) and also indicated the presence of two potential outliers, suggesting that items in the pleasure subscale are subject to more fluctuation and extraneous influence than other subscales. Self-realisation scores between baseline and retest were again moderately stable ( $ICC=.698$ ) with a 95% CI of .495 to .829 ( $F(38,39) = 5.618, p < .001$ ).

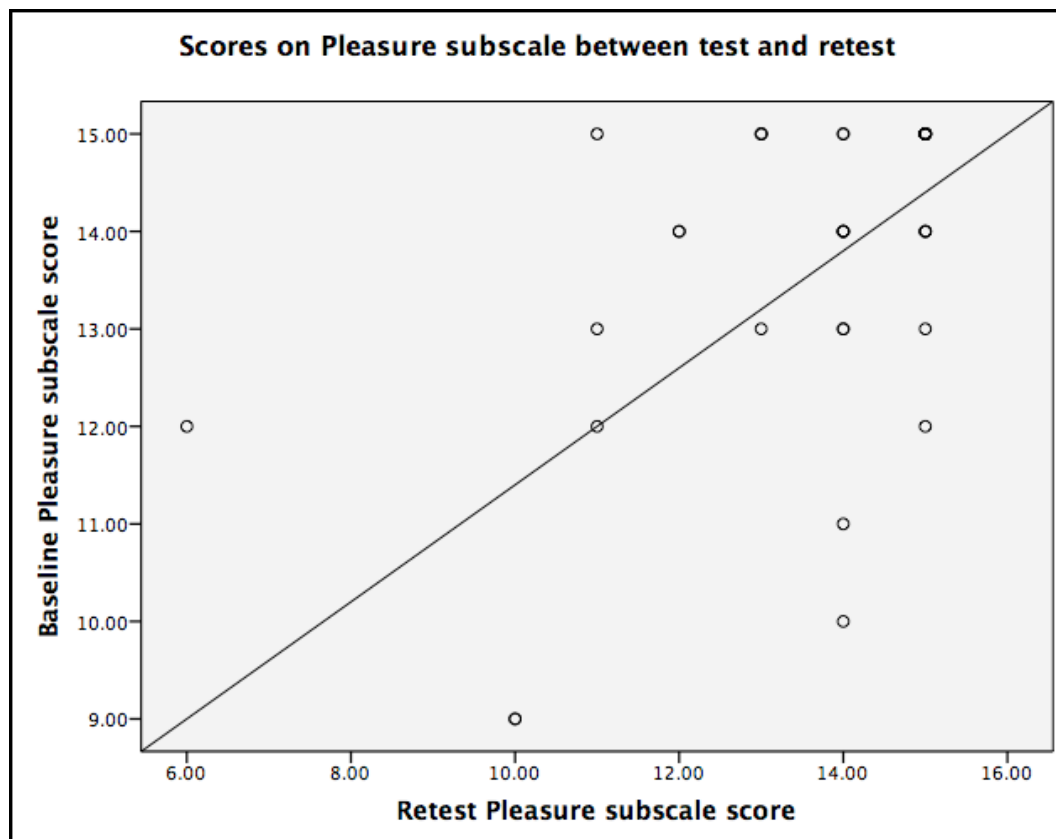


Figure 7.7 Scatter plot of scores on Pleasure subscale of CASP-19 between test and retest for psychometric study

#### 7.4.4.4 Convergent and concurrent validity

Pearson's R correlations were conducted between all subscales on the CASP-19 and the GDS to assess convergent validity. All subscales (control:  $r = -.565$ , autonomy:  $r = -.524$ , self-realisation:  $r = -.630$ , pleasure:  $r = -.480$ ) and the CASP-19 overall ( $r = -.739$ ) emerged as significantly correlated with the GDS (all  $p < .001$ ). As both the QoL-AD and CASP-19 are quality of life measures, Pearson's R correlations were used as an

indication of concurrent validity or how well one measure correlates with a 'gold standard' of the concept in question. Control ( $r = .539$ ), autonomy ( $r = .535$ ), self-realisation ( $r = .642$ ) and pleasure ( $r = .362$ ) were all significantly correlated with the QoL-AD ( $p < .001$ ), as was the CASP-19 overall ( $r = .705, p < .001$ ).

An independent samples t-test indicated that people who scored less than five on the GDS scored significantly higher on the CASP-19 ( $M = 57.04$   $SEM = 1.59$ ) than those who scored ten or greater on the GDS ( $M = 44.28$   $SEM = .557$ ) ( $t(196454029) = 11.311, p < .001$ ).

## 7.5 Discussion

This chapter details the first attempt to assess positive characteristics in a quantitative manner for people with dementia. Results indicated that people with dementia were able to use the measures without major issue and a significant proportion of participants were able to complete them by self-report.

Whilst participants were more or less evenly split between male and female, more males took part in the current study than women. Usually in dementia research, participants are predominantly women. However, the inclusion criteria specified participants should be deemed able to provide informed consent and, therefore, were more likely to be in the milder stage of dementia. This combined with the average age of 77 years meant a higher proportion of men appeared to have been captured here than other research, reflecting the methods of recruitment used for this study.

Internal consistency for both the PPOM V3 and EID-Q V3 was acceptable and test-retest reliability ranged between moderate to good. Whilst test-retest reliability was not

absolute, as it rarely would be, the range of moderate to good suggests that positive concepts for people with dementia, whilst subject to some fluctuation, largely remain stable. Only two participants were identified as fluctuating largely. One participant scored high at baseline on the PPOM V3 and then low at retest and another participant had the reverse of this. The former participant, whilst scoring 58 at baseline, only scored 20 at retest. All other measures remained stable and the participant did not identify any mental/ physical health problems or changes to medication between baseline and retest. It is, therefore, difficult to draw conclusions. It may be that there was a significant life event that this study was not designed to pick up, or it may be that for this particular participant hope and resilience were more of a state rather than an ingrained personality trait and therefore, subject to variability (Chaplin, John, & Goldberg, 1988).

Analysis of the CASP-19 indicated that some items may not hold relevance for people with dementia. In particular, the autonomy subscale fell below the acceptable limit for a Cronbach Alpha, limiting the degree to which results can be meaningfully interpreted. Both items six and 9 are suggested as being in further need of consideration when applied to older adults with dementia. Furthermore, analysis of pleasure subscale indicated that test-retest reliability for these items was less than expected. These items, in particular, may be more subject to fluctuation than other subscales in the CASP-19 and warrant further attention.

Correlations for all measures were in the expected direction and statistically significant. Correlations ranged from a low of  $r = .362$  between the pleasure subscale of the CASP-19 and QoL-AD and highs of  $r = .704$  between the QoL-AD and EID-Q, and  $r = .705$  between the QoL-AD and the CASP-19. Whilst statistically significant, clinical

significance is harder to define, as there are no other studies to compare the results here with. It is suggested that correlations above  $r = .40$  are 'moderate' whilst  $r = .60 - .79$  are 'strong' (Evans, 1996). However, it has also been suggested that correlations above .40 should be considered clinically significant (Dunn, 2000). Correlations any higher here may have indicated that positive measures were conceptually identical to existing quality of life measures. As such moderate correlations were considered clinically significant and indicative that measures here, whilst measuring positive concepts, were distinct from quality of life.

### ***7.5.1 Methodological problems and limitations***

Originally, retesting was on an optional basis for participants and only took part at one NHS trust (NELFT). However, recruitment at other NHS trusts progressed much quicker than anticipated. As such, the total number of participants to have completed the study came close to the original upper recruitment target of 195 without an adequate number of participants completing the retest. After the second substantial amendment was approved (section 7.3.2), participants completed one baseline assessment and one retest as standard. Following this, there was a significant improvement in the rate of retest data but this was still short of the intended target of 50. Future researchers may wish to examine the stability of these measures with larger samples.

Participants here were predominantly White-British or White-Other, with Black and Minority Ethnic Groups (BME) accounting for only six participants. Consequently, psychometric properties reported here are primarily for White-British older adults. As such, inferences cannot be drawn as to the cross-cultural validity of these measures. Whilst it has been noted that some positive traits are universally similar with evidence documenting them in 54 countries (Park, Peterson & Seligman, 2006), the degree and

variability to which people from different cultures or religions experience these concepts and how they relate to depression and quality of life could not be examined here.

### ***7.5.2 Conclusion***

Psychometric properties were adequate for the PPOM V3, EID-Q V3 and CASP-19. No items were identified as redundant in the internal consistency analysis and, therefore, novel measures will hereafter be referred to as the PPOM and the EID-Q to illustrate that they were final versions and were not further amended. Following a psychometric analysis, factor structure was next explored to provide further evidence of all measure's reliability and validity (Chapter 8).

## 8. Factor structure of the PPOM, EID-Q and CASP-19

### 8.1 Introduction

Factor Analyses are explorative analyses used to identify latent concepts in a measurement model. For psychometric purposes, factor analyses evidence the content validity of novel measures by exploring whether items share the same underlying latent factor (Thompson, 2004). Structural Equation Modelling allows the testing of multiple independent and dependent variables, where basic statistical tests do not allow for the testing of theoretical relationships between multiple variables. Furthermore, SEM techniques also take into account measurement error. A simple regression model usually uses the average of variables or items in a measure whereas a factor analysis uses individual variables and, therefore, a factor analysis is more valid for psychometric analyses as it bypasses measurement error in more simple regression models.

In these processes, diagrams are used to denote the relationships between variables and their latent factors. Variables are denoted by rectangles, factors by ovals, causal relationships by one headed arrows and covariance by double headed arrows. Variable error is represented by 'Err' followed by the name of the variable and factor loadings are denoted by ' $\beta$ '.

To assess the underlying factor structure of The Positive Psychology Outcome Measure (PPOM), Engagement and Independence in Dementia Questionnaire (EID-Q) and Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19) a combination of Exploratory and Confirmatory approaches were used.

## 8.2 Aims

The aim of this chapter was to explore the factor structure of novel measures using best practice Structural Equation Modelling (SEM) techniques. Therefore, the sub-aims of this chapter were to:

1. Explore the underlying factor structure of the PPOM, EID-Q and CASP-19 without imposing preconceived structure on the outcome.
2. Derive one or more best models for the relationships between observed variables and potential latent concepts.

## 8.3 Methods

### ***8.3.1 SECTION A: Model Construction using an EFA.***

An Exploratory Factor Analysis (EFA) is a variable reduction technique, which identifies the number of latent constructs and an underlying factor structure of a set of variables. It hypothesises an underlying construct, which is not a variable that is overtly measured. It is traditionally used to explore the possible underlying factor structure of a set of measured variables without imposing any preconceived structure on the outcome (Child, 1990). Factor analysis extracts variable variance based on squared multiple correlations in the diagonal of the matrix. This differs from a Principal Component Analysis (PCA), which is sometimes used in psychometric analysis, where PCAs extract variable variance but from the diagonal of the correlation matrix where each variable has a variance of 1. Therefore, a PCA reproduces all variable variance, whereas an EFA only accounts for variance in the partial correlation of each variable and so does not include all variable variance (Schumacker, 2015).

Data was randomly halved using Statistical Package for Social Scientists (SPSS) random cases generator and this half was imported into Mplus, alongside all variables in

the study. Mplus is a latent variable statistical programme with a wide range of analysis capabilities. Random halving of data is best practice for SEM and allows for the building of a model before confirming of the model with the second half of the data in a confirmatory factor analysis (CFA). Syntax was entered into Mplus for performing an EFA with a minimum of one factor and a maximum of three. Syntax was also entered for providing scree plots within the output, for a visual representation of factor loadings. Factors were then extracted using visual examination of scree plots and using Kaiser's criterion, which considers variables with an eigenvalue greater than one as factors (Kaiser, 1960). Eigenvalues indicate the amount of variance that can be explained by each variable within a covariance matrix and are denoted by the formula  $E = V'R$  where 'E' denotes eigenvalues, 'V' denotes eigenvectors or weights and 'R' denotes correlation matrix (Schumacker, 2015). Using a combination of both theory and data evidence, factors are then given labels that denote the concept that is theorised to be measured.

### **8.3.2 SECTION B: Model validation using a CFA**

Factor structures identified in an EFA are then usually confirmed using a Confirmatory Factor Analysis (CFA). A CFA allows the testing of a hypothesis that a relationship between observed variables and their latent underlying construct exists and is based on theoretical knowledge, empirical research or both (Kline, 2010). A CFA also examines the testing of 'goodness of fit' of a measurement model to data and should always precede SEM as, if a factor structure has a poor fit to data, any extension of hypotheses regarding causation pathways are unlikely to fit data well also (Schumacker & Lomax, 2016). Furthermore, an EFA describes a model that best fits the data but does not say if the model is a 'good' model. A CFA then describes whether or not the model is good enough.



The remaining half of the data that was not used in the EFA stage was imported into MPlus and the factor structure in the EFA stage was applied as confirmatory at this stage. To test the fit of this model to the remaining data a number of fit indices were used. Firstly, the chi-squared statistic was used to analyse whether the observed data departed significantly from the expected data in the proposed measurement model. A significant chi-squared differences test indicates that the relationship between the observed and expected data is different and, therefore, the model is a ‘bad fit’. However, sample sizes impact on the chi-squared test and, with a moderately large sample size, trivial differences between observed and expected data can cause significant chi-squared statistics. Therefore, other fit indices were needed to fully examine whether the proposed model was a good fit. To minimise the possibility of type I and type II errors, it is recommended that one incremental fit index is used, usually a Comparative Fit Index alongside the Standardised Root Mean Square Residual (SRMR) and the Root Mean Square Error of Approximation (RMSEA). CFI values of  $>.90$  are generally acceptable whilst, SRMR values should be below  $<.08$ . RMSEA values of  $<.06$  are generally considered to indicate good models (Hu & Bentler, 1999), whilst values between  $.06$  and  $.08$  suggests acceptable model fit. Scores above one are considered to have poor fit. However, these are considered guidelines and alternative values are suggested elsewhere (Steiger, 2007).

### ***8.3.3 SECTION C: Data integration and final validation***

As models were constructed and validated using random halves of the data, both sets of data were reintegrated. Following integration, the factor structure in the CFA stage was again applied as confirmatory and fit indices were re-examined to ensure the model was still an adequate fit to data.

## 8.4 Results

Data from the psychometric study (Chapter 7) and a small amount of additional data ( $n=21$ ) derived from a final year clinical psychology trainee project (Appendix 2.7) was randomly split using SPSS and labelled ‘1-Construction Half’ and ‘0-Validation Half’. The construction half of the data represented 130 participants, whilst the validation half consisted of 107 participants ( $n=237$ ).

### 8.4.1 *The Positive Psychology Outcome Measure (PPOM)*

#### 8.4.1.1 *SECTION A: Model Construction using an EFA*

The 16 items on the PPOM were entered into Mplus using maximum likelihood and Geomin Oblique rotations. Oblique rotations were used to allow correlations between factors, as hope and resilience were deemed to be theoretically related. A minimum of one and a maximum of 3 latent factors were specified in the model output. Eigenvalues indicated that two factors were present (8.681 and 1.135) but a substantial drop between factors one and two were observed on the scree plot (Figure 8.1).

As the eigenvalues indicated a two-factor solution was most appropriate, factor loadings for this structure were assessed. Loadings indicated that items loaded onto two factors successfully, with the majority of the hope items loading onto factor one and the resilience items loading onto a second factor (Figure 8.2). Four items loaded onto both factors (one hope and three resilience) and there was a significant correlation between these factors ( $.716, p < .05$ ). Therefore, a two-factor structure was most appropriate. Factor 1 was named ‘hope’ and factor two ‘resilience’.

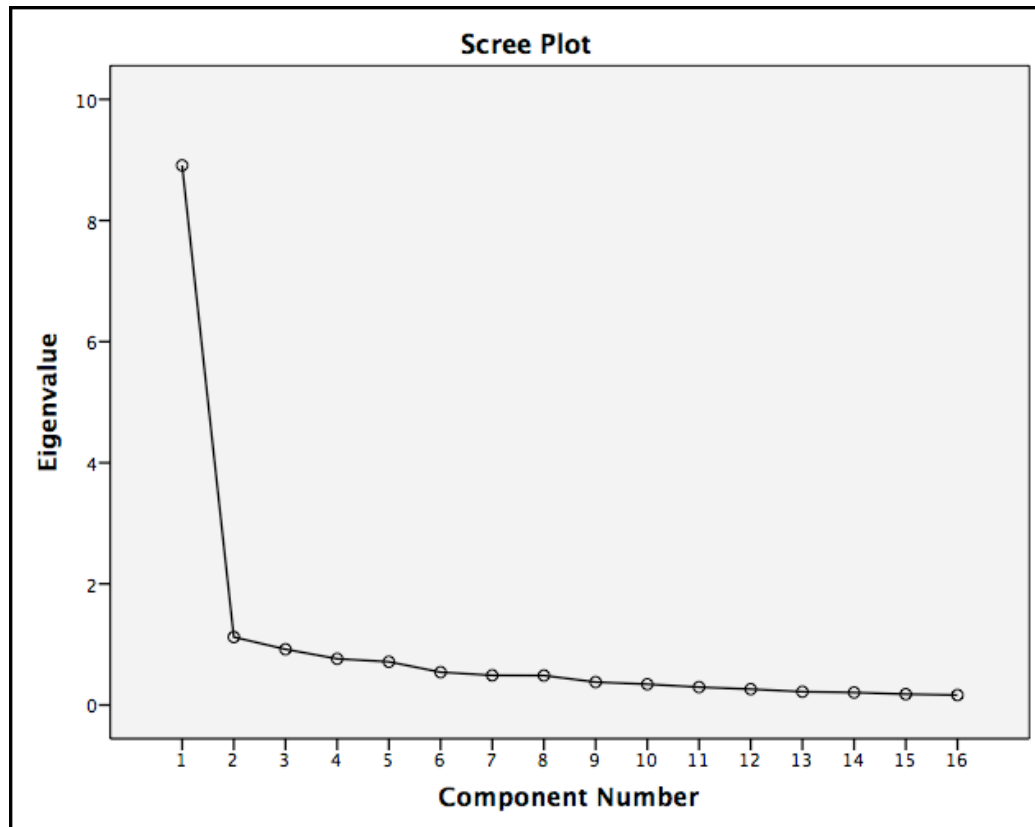


Figure 8.1 Scree plot of eigenvalues for PPOM in EFA

Scale Items	Geomin Rotated Loadings	
	Factor 1	Factor 2
I have a positive outlook on life	0.424*	0.270
I can see positive things in difficult situations	0.652*	0.072
I can recall happy/ joyful times	0.439*	0.181
I have inner strength	0.401*	0.390*
I can give and receive care/ love	0.699*	- 0.007
I have a sense of direction in life	0.540*	0.221
I believe that each day has potential	0.899*	- 0.022
My life has value and worth	0.697*	0.120
I am able to adapt to things	0.388*	0.373*
I am able to deal with whatever happens	0.147	0.650*
I am able to see the humorous side	0.291*	0.397*
I can cope with stress well	- 0.167	0.977*
I can bounce back	0.124	0.714*
I can stay focused	0.286*	0.515*
I am an emotionally strong person	0.118	0.721*
I can handle unpleasant feelings	- 0.005	0.851*

\* Statistically significant at  $p < .005$ .

Figure 8.2 Factor loadings of the PPOM in EFA

#### 8.4.1.2 SECTION B: Model Validation using a CFA.

The validation half of data was used to establish whether the factor structure in the EFA stage (2 factors) was an adequate model to fit the data. Factor one was labelled ‘h’ to represent hope and consisted of items 1-8 on the hope subscale. Factor two was labelled ‘r’ to represent resilience and consisted of items 9-16 on the resilience subscale. As some items in the EFA loaded onto both latent factors, and correlation was observed between the two factors, no restrictions were put on correlations between factors during the CFA stage. This meant that latent factors were allowed to correlate freely. The proposed model represented a moderate fit to the data. Whilst the chi-squared test was significant, the CFI, RMSEA and SRMR were in the specified cut offs (Table 8.1).

*Table 8.1 CFA validation half fit indices for two-factor structure of PPOM*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>2 Factors</b>	185.394*	103	0.914	.08	.05

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

The model results indicated that each variable loaded onto its latent factor. Factor loadings ranged from 0.317 to 1.427 and all were statistically significant, indicating a good fit (Figure 8.3). The two latent factors shared some covariance ( $r = .504$ ), which was expected and at an acceptable level. Average variance explained by the two factors were  $R^2 = .46$  for hope and  $R^2 = .593$  for resilience

#### 8.4.1.3 SECTION C: Data Integration and Final Validation

Data used in both the construction stage and validation stage, were re-integrated and the CFA, using the factor structure identified in the EFA and confirmed in the CFA validation stage, was re-run to check whether the model was still a moderate fit when all data was used. Again, latent factors were allowed to correlate freely to examine covariance between the hope factor and resilience factor. The two-factor structure again had a moderate fit. Again, the Chi-Square goodness of fit was statistically significant, indicating that the data did depart from the norms of the model, but other fit indices had improved (CFI, RMSEA and SRMR) were acceptable (Table 8.2).

*Table 8.2 CFA Integrated data fit indices for two-factor structure of PPOM*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>2 Factors</b>	247.05*	103	.932	.079	.044

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

Factor loadings at this stage ranged from 0.468 - 1.293, with more loadings above 1 than in the validation stage (Figure 8.4). The two latent factors shared some covariance again ( $r = .494$ ) and the average variance explained by the two factors was  $R^2 = .49$  for hope and  $R^2 = .59$  for resilience.

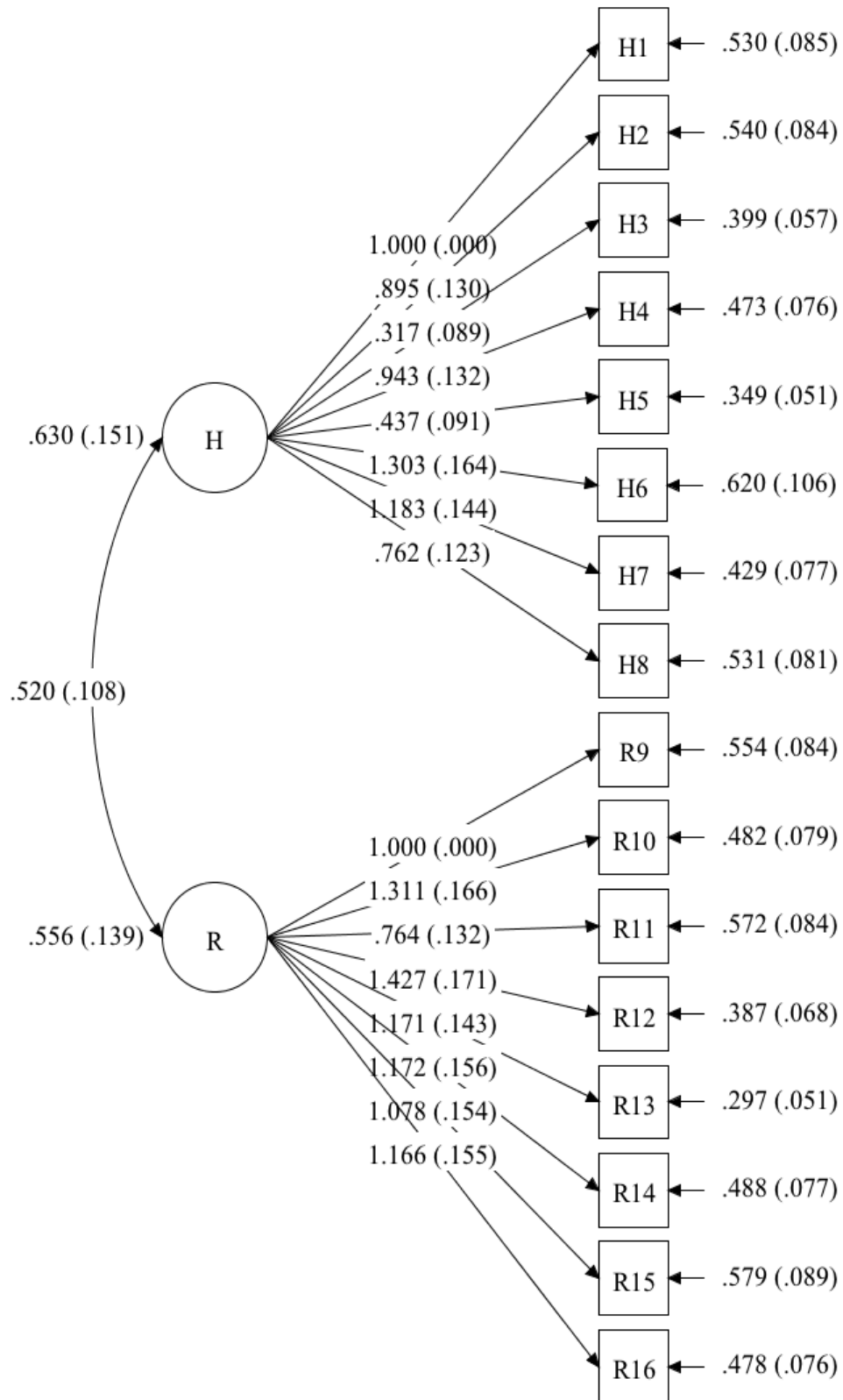


Figure 8.3 CFA Validation half factor loadings for PPOM

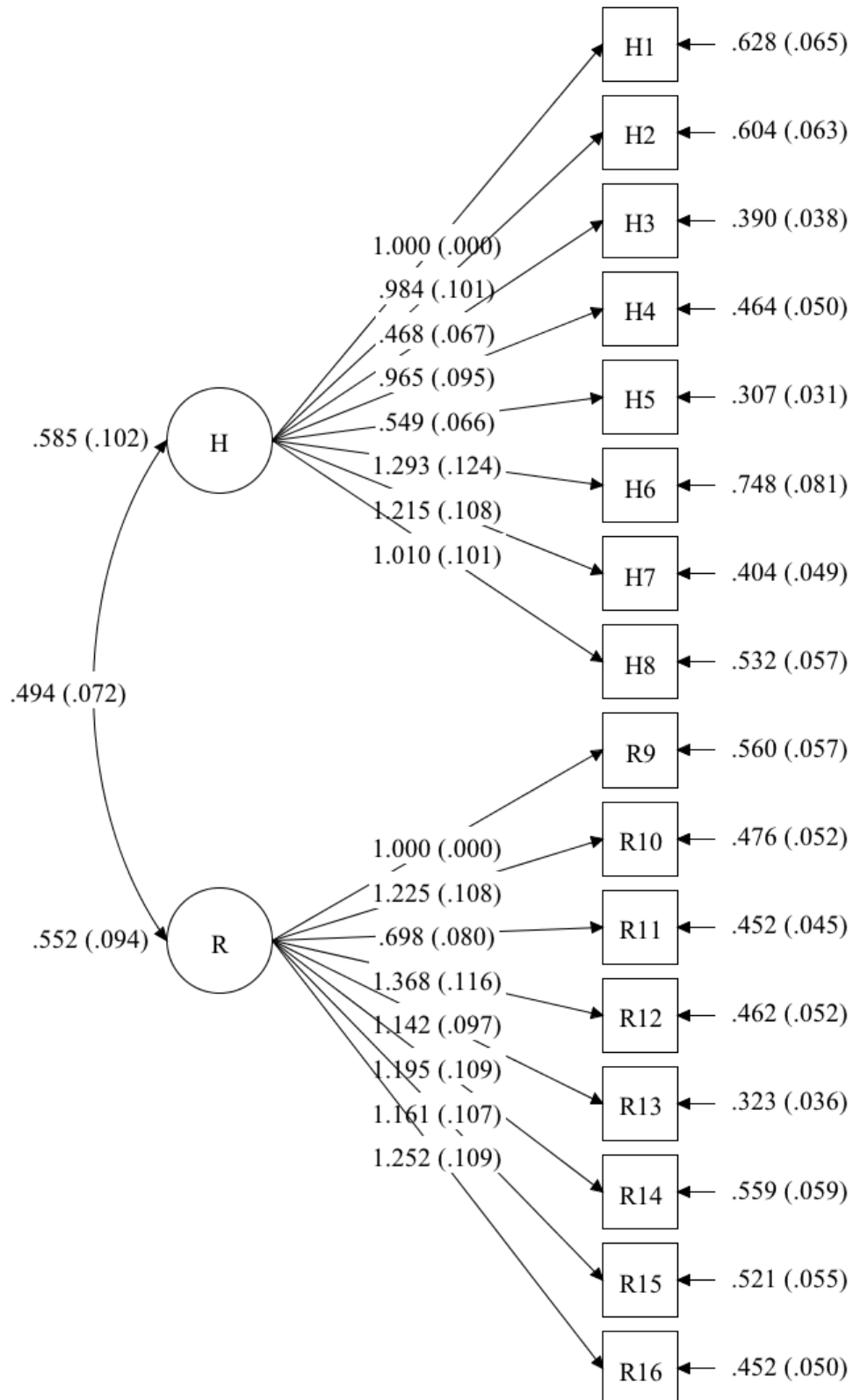


Figure 88.4 CFA Integrated data factor loadings for PPOM

### 8.4.2 The Engagement and Independence in Dementia Questionnaire (EID-Q)

#### 8.4.2.1 SECTION A: Model Construction using an EFA

The 26 items of the EID-Q were loaded into Mplus in the same manner as the PPOM. Eigenvalues indicated the presence of five factors all above 1. However, upon inspection of the scree plot (Figure 8.5), a substantial drop was noted between factors one and three. Using the structure correlations, a two-factor structure was deemed most appropriate. Correlations between items on each of the two factors were adequately correlated (Figure 8.6). Factor 1 was termed ‘Sense of Independence’ whilst factor two was termed ‘Social Engagement’. These factors were also significantly correlated with each other ( $.454, p < .05$ ).

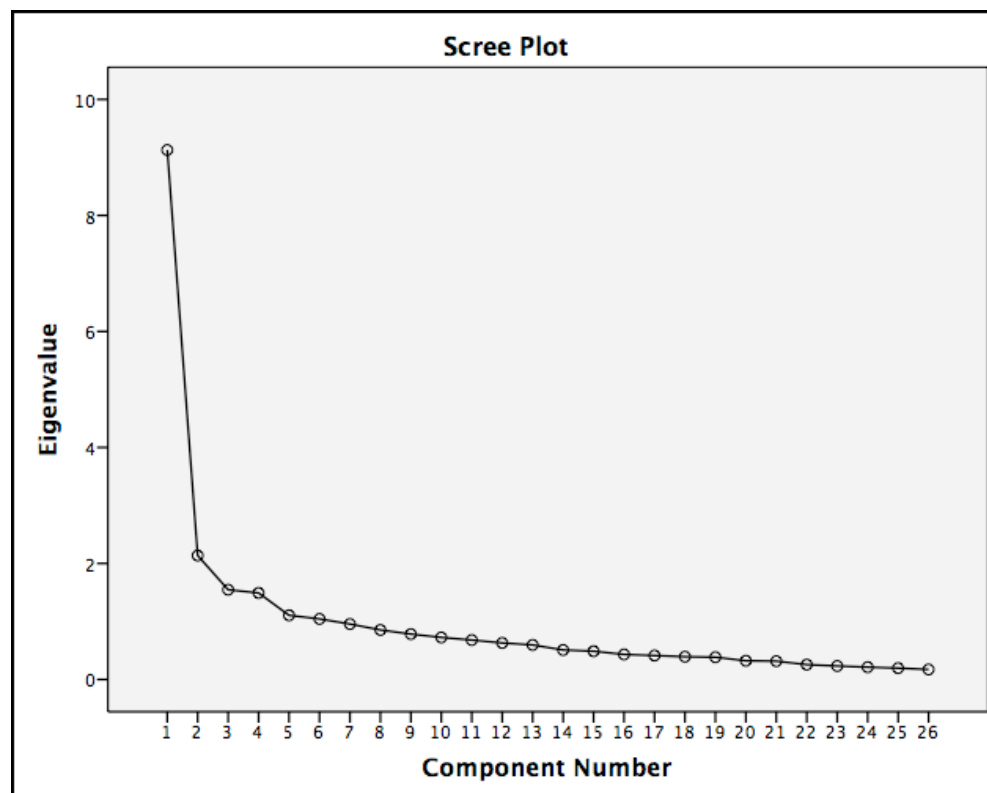


Figure 8.5 Scree plot of eigenvalues for the EID-Q in EFA



Scale Items	Geomin Rotated Loadings	
	Factor 1	Factor 2
I can look after myself as much as I need to	0.670*	- 0.145
I have people who I can talk to if I need to	0.231	0.397*
I have hobbies/ activities that I enjoy doing	0.580*	0.158
I have a role in my social circle	0.316*	0.257*
I am a burden to others	0.535*	0.024
I enjoy conversations with others	0.193	0.366*
I can make my own decisions as much as I'd like to	0.675*	- 0.028
There are people I could ask for help if I need to	0.167	0.464*
I'm confident in making decisions	0.830*	- 0.255
I am often ignored by those around me	- 0.042	0.405*
I can do activities that are important to me	0.669*	0.017
I can get in touch with my friends/ family if I need to	0.297*	0.499*
People take decisions away from me	0.226	0.293*
My friends/ family care about me	- 0.153	0.718*
I can arrange my life in a way that suits me best	0.536*	0.226
I can help the people I care about	0.651*	0.066
I feel I am active in everyday life	0.636*	0.173
I can take part in groups/ activities with others	0.558*	- 0.030
I can adapt my wishes to be in line with what I can do	0.524*	0.190
I feel that my friends/ family want to spend time with me	0.062	0.687*
I can make changes to my life to match my abilities	0.503*	0.396*
I can confide in my friends/ family	0.005	0.635*
I can get myself food if I need to	0.411*	0.231
I can help my friends/ family as much as I would like	0.862*	- 0.078
I keep myself busy with hobbies/ activities	0.539*	0.134
I feel connected to others	0.347*	0.444*

\* Statistically significant at  $p < .005$

Figure 8.6 Factor Loadings of the EID-Q in EFA

#### 8.4.2.2 SECTION B: Model Validation using a CFA

The validation half of the data was used to confirm the two-structure factor solution identified in the EFA stage. Syntax was entered into Mplus to specify the two latent factors 'Sense of Independence' and 'Social Engagement' and that these latent factors should be allowed to correlate freely. The proposed model indicated that the model was not an adequate fit, with all indices falling below or above acceptable limits (Table 8.3). However, all factor loadings at this point were significant and ranged from 0.460 –

2.181 (Figure 8.7). A small amount of covariance was observed between the two factors ( $r = .147$ ).

*Table 8.3 CFA validation half fit indices for two-factor structure of EID-Q*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>2 Factors</b>	640.697*	298	0.677	.107	.093

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

#### 8.4.2.3 SECTION C: Data Integration and Final Validation

Data were re-integrated into Mplus, to ensure that the poor fit was not a result of the decreased sample size, as both the construction and validation stage used the random halves of data. Again, the proposed model was not an adequate fit. Whilst some indices had improved, it was not within an acceptable range of the recommended cut-offs (Table 8.4). Factor loadings at this stage ranged between .538 – 2.064 (Figure 8.8).

*Table 8.4 CFA integrated fit indices for two-factor structure of EID-Q*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>2 Factors</b>	825.013*	298	0.763	.089	.074

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

In the EFA stage, the two-factor solution was selected based on data and theory.

However, as discussed in Chapter 5 (section 5.4.2), it may be that these concepts are much more closely related than anticipated. To examine whether this was the case, a second confirmatory factor analysis was conducted with a one factor solution. This factor was named ‘Interdependence’ to reflect the interrelatedness of sense of independence and social engagement themes. At this stage, all factor loadings were

significant and ranged from .521 – 1.535 (Figure 8.9). However, all other fit indices were worse than in the two-factor structure solution (Table 8.5). Therefore, the EFA stage was revisited.

*Table 8.5 CFA integrated fit indices for one-factor structure of EID-Q*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>1 Factor</b>	902.75*	299	0.738	.095	.078

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

As neither the one-factor nor two-factor solution was acceptable, a series of additional analyses were run to test competing models. Using data from the EFA stage, a five-factor structure appeared to be an acceptable fit. Furthermore, item loadings indicated that there were a number of subscales within the measure that had not been anticipated. The measure was subsequently split into five subscales: Decision making (Dec), Activity Engagement (Act), Support Network (SN), Activities of Daily Living (ADL) and Reciprocity (Rec) (Appendix 1.7) and a second order analysis was conducted using ‘social engagement’ and ‘independence’ as the latent factors. This solution was subject to a CFA to establish whether this was an acceptable model of the data. Fit indices indicated that the model was a significant improvement on those preceding it (Table 8.6). The RMSEA and SRMR were within the specified cut offs but the CFI was still below the acceptable limit of  $>.9$ .

*Table 8.6 CFA integrated fit indices for five-factor, second order factor structure of EID-Q*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>5- Factor, second order.</b>	691.260*	293	0.821	.078	.069

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

In the five-factor and second order model, all items loaded onto their respective factors and all factors loaded onto the two latent second order factors (Figure 8.10). This meant that preceding models were rejected and the five-factor model accepted. Furthermore, both latent factors were significantly correlated with each other ( $r = .526, p < .001$ ).

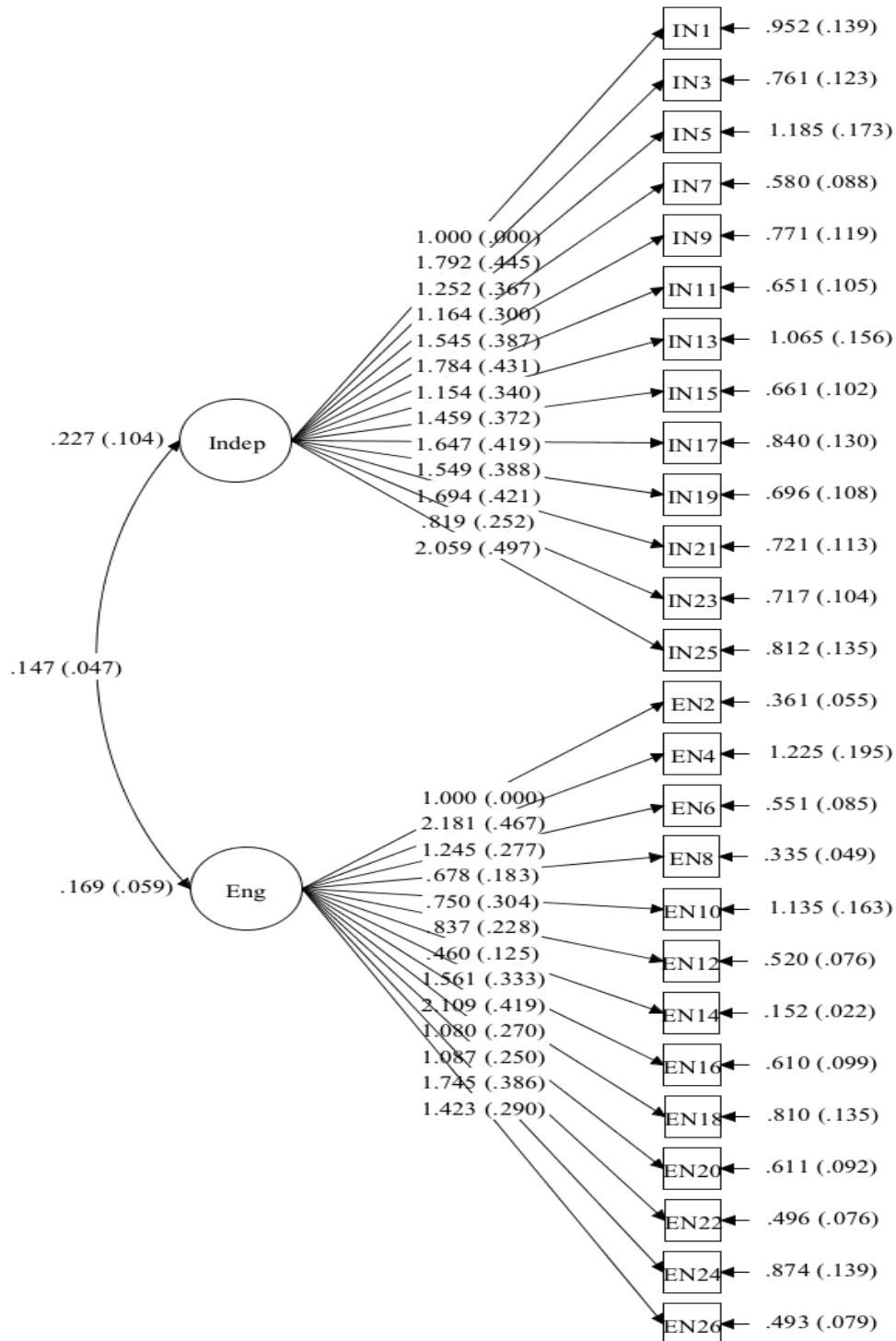


Figure 8.7 CFA Validation half factor loadings for EID-Q

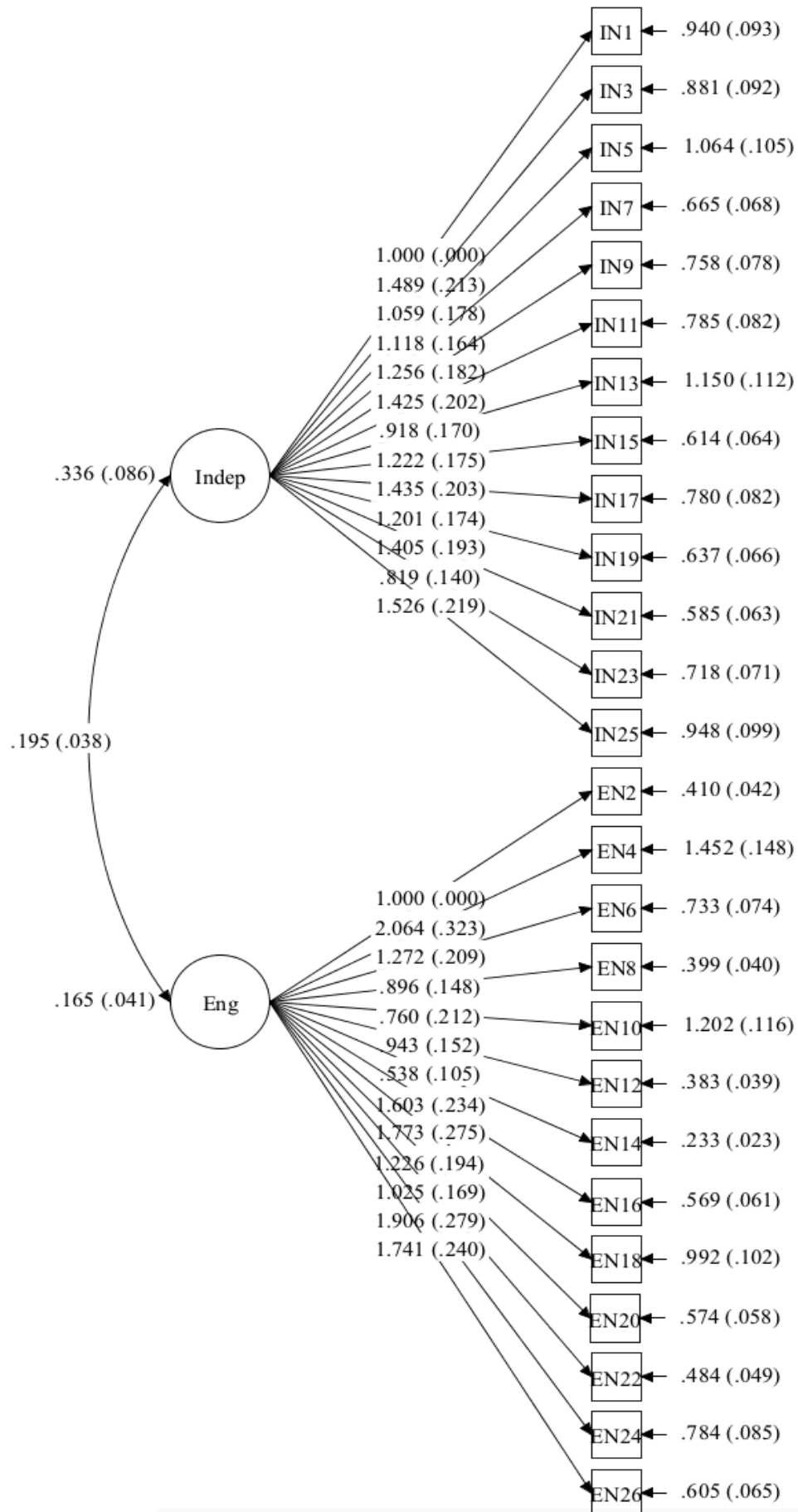


Figure 8.8 CFA integrated factor loadings for EID-Q

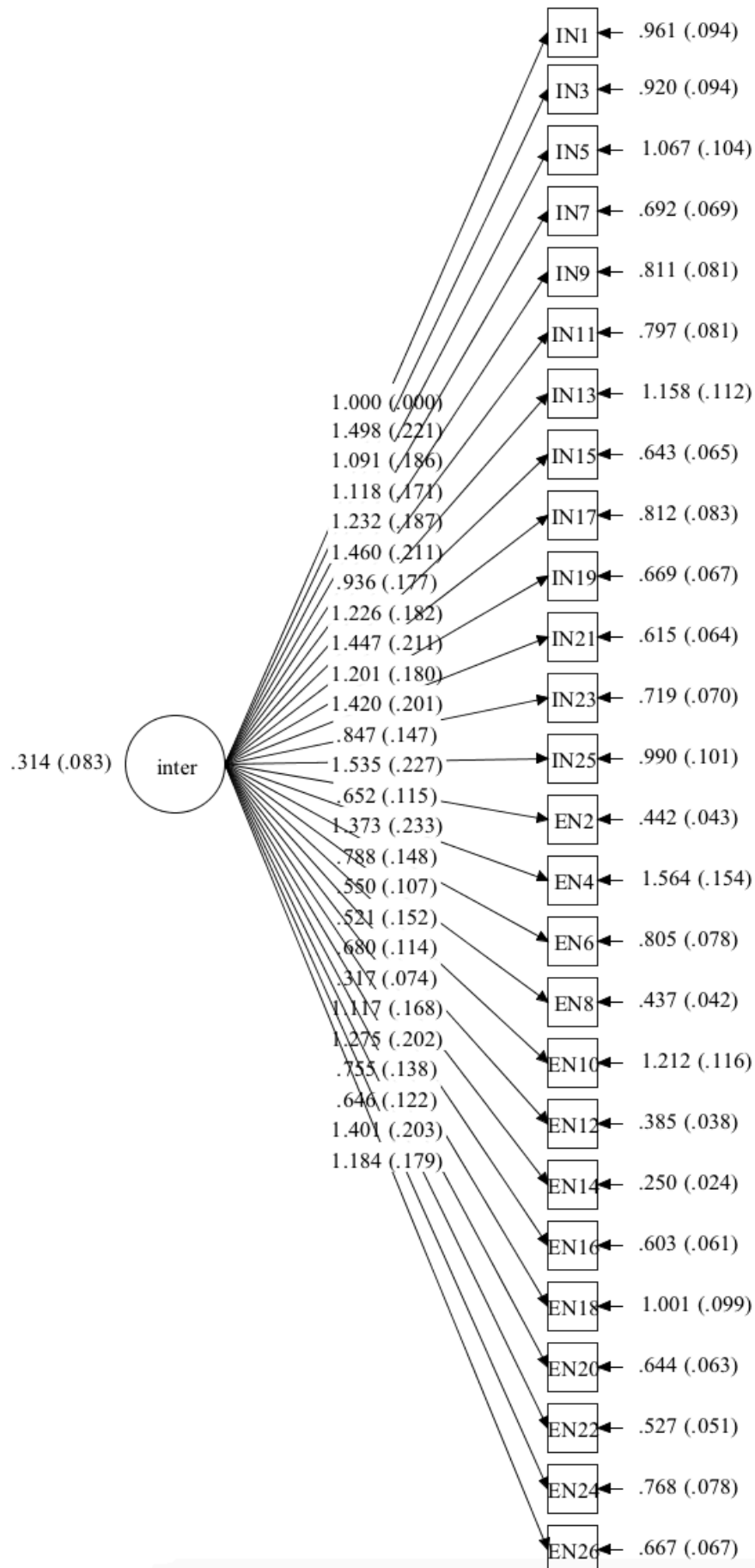


Figure 8.9 CFA integrated factor loadings for EID-Q using 1 factor solution

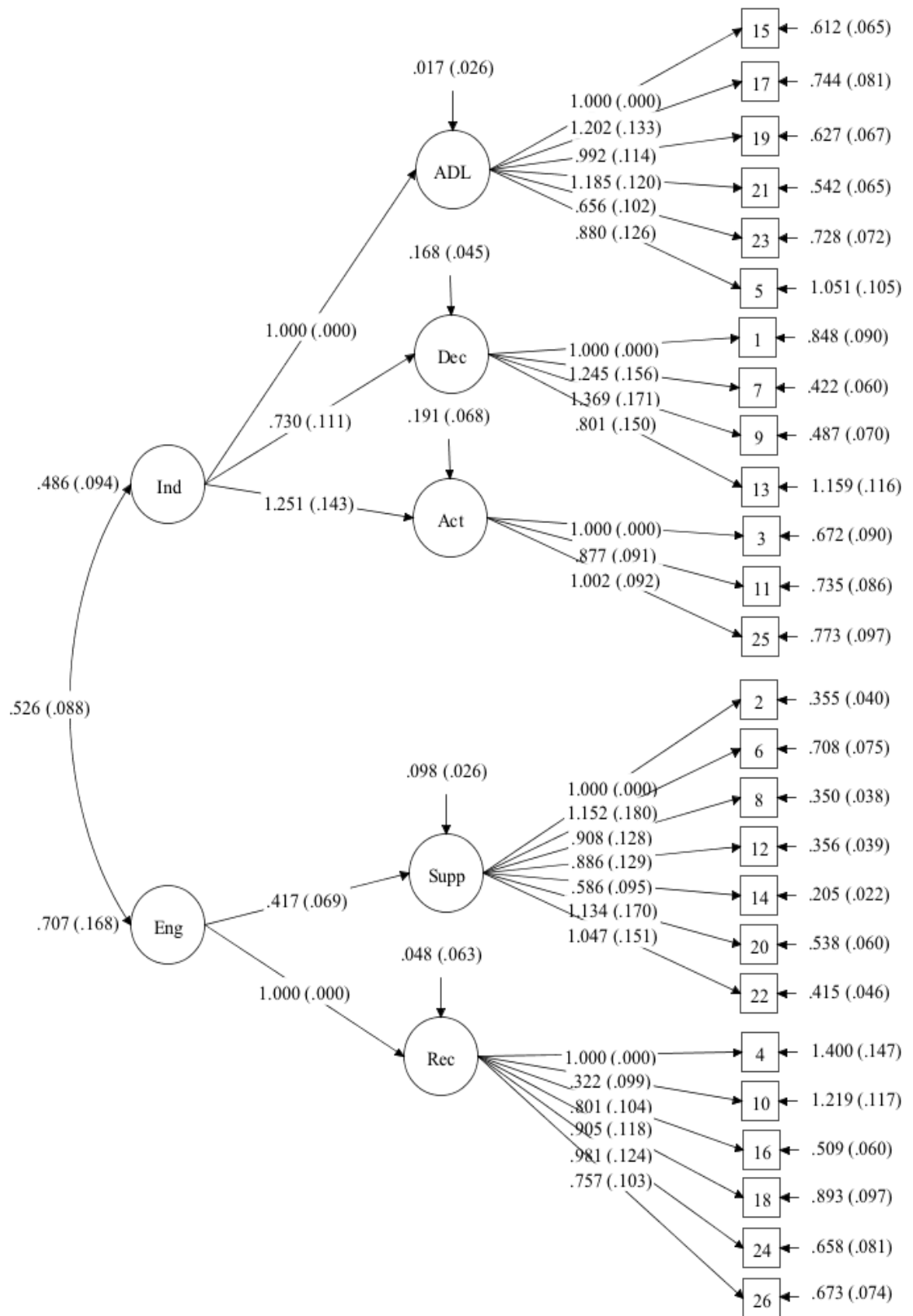


Figure 8.10 CFA integrated factor loadings for five-factor EID-Q

### 8.4.3 The Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19)

#### 8.4.3.1 SECTION A: Model Construction using an EFA

The 19 items of the CASP-19 were loaded into Mplus and between one and five factors were requested using syntax to account for the four subscales of the CASP-19.

Eigenvalues indicated a six-factor structure solution, with values ranging from 5.530 to 1.016. A scree plot indicated a substantial drop after factor one, with factor two having an eigenvalue of 2.163 (Figure 8.11). Factors three, four, five and six had low eigenvalues in comparison (1.782 – 1.016).

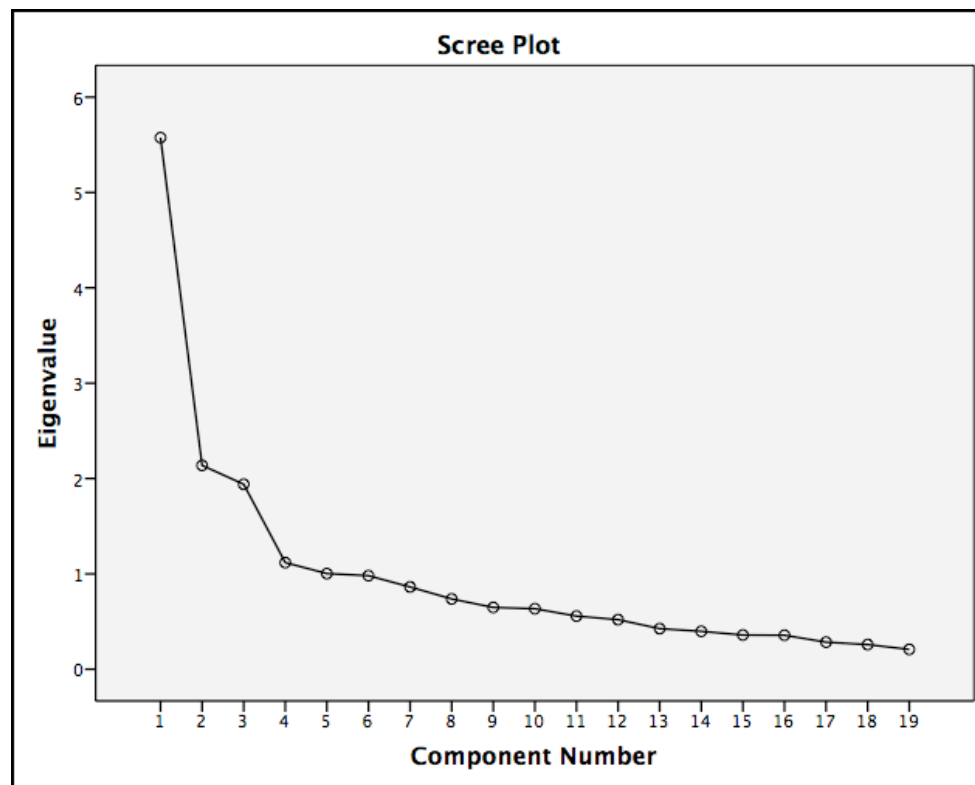


Figure 8.11 Scree plot of eigenvalues for CASP-19 in EFA

The majority of items loaded onto one latent factor, with the exception of item six ‘family responsibilities prevent me from doing what I want to do’ and item 9 ‘shortage of money stops me from doing the things I want to do’. Both of these items were in the autonomy subscale, already identified as problematic in Chapter 7 (section 7.3.4). This latent factor was termed ‘quality of life’ (Figure 8.12).



Scale Items	Geomin Rotated Loadings
	Factor 1
My age prevents me from doing the things I would like to	0.341*
I feel that what happens to me is out of my control	0.490*
I feel free to plan for the future	0.614*
I feel left out of things	0.378*
I can do the things that I want to do	0.658*
Family responsibilities prevent me from doing what I want to do	0.120
I feel that I can please myself with what I can do	0.535*
My health stops me doing the things I want to do	0.392*
Shortage of money stops me from doing the things that I want to do	- 0.043
I look forward to each day	0.685*
I feel that my life has meaning	0.604*
I enjoy the things that I can do	0.577*
I enjoy being in the company of others	0.386*
On balance, I look back on my life with a sense of happiness	0.343*
I feel full of energy these days	0.608*
I choose to do things that I have never done before	0.414*
I feel satisfied with the way my life has turned out	0.542*
I feel that life is full of opportunities	0.641*
I feel the future looks good for me	0.635*

Figure 8.12 Factor loadings of the CASP-19 in EFA

#### 8.4.3.2 SECTION B: Model Validation using a CFA

Using the one latent factor structure documented in the EFA stage, a CFA was performed on the construction half of the data. Factor loadings ranged from 0.386 - 2.033 and all were significant with the exception of item six ( $p = .105$ ). This item, whilst statistically significant, had already been identified as problematic in the psychometric stage and the EFA stage. Therefore, the analysis was re-run omitting this item. However, fit indices indicated that this model was potentially problematic (Table 8.7) with the CFI, RMSEA and SRMR all falling above or below their respective limits.

Table 8.7 CFA validation half fit indices for one-factor structure of CASP-19

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>1 Factor</b>	286.7*	152	0.76	.094	.086

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

Without item six, the model was slightly improved (Table 8.8). Furthermore, all items now loaded significantly onto the latent quality of life factor with loadings ranging from 0.683 - 2.036 (Figure 8.13). However, whilst fit indices slightly improved, all were still below acceptable limits.

Table 8.8 CFA validation half fit indices for one-factor structure of CASP-19 (item 6 omitted)

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>1 Factor</b>	249.6*	135	0.793	.092	.085

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

#### 8.4.3.3 SECTION C: Data Integration and Final Validation

Item six was omitted and the CFA was rerun using all data. However, fit indices were significantly worse and item 9 did not significantly load onto the latent quality of life factor ( $p = .185$ ).

Therefore, item 9 was omitted and the CFA with integrated run again. This also resulted in a worse model and, consequently, both items six and 9 were re-integrated into the CFA. The Chi-Squared slightly improved whilst the RMSEA and SRMR increased slightly (Table 8.9). However, fit indices were again not acceptable.

All items loaded onto the latent quality of life factor, with the exception of item 9 ( $p < .163$ ) (Figure 8.14). However, when the analysis was rerun with just item 9 omitted, the model worsened. Therefore, item 9 was kept in the model.

*Table 8.9 CFA integrated fit indices for one-factor structure of CASP-19*

	$\chi^2$	$df$	CFI	RMSEA	SRMR
<b>1 Factor</b>	482.06*	152	0.725	.099	.083

$\chi^2$ = Chi-Square goodness of fit;  $df$ = degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

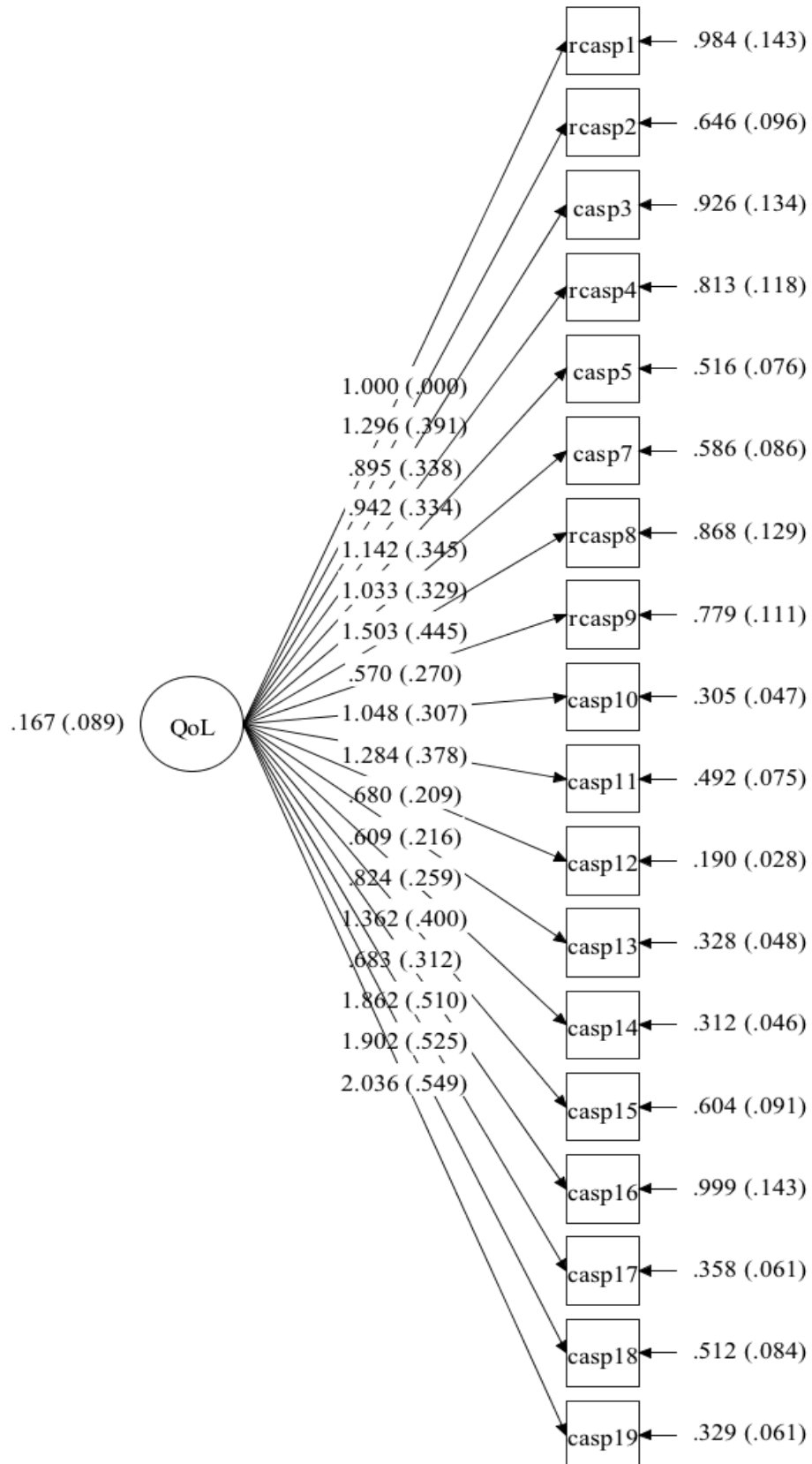


Figure 8.13 CFA validation half factor loadings for CASP-19 without item 6

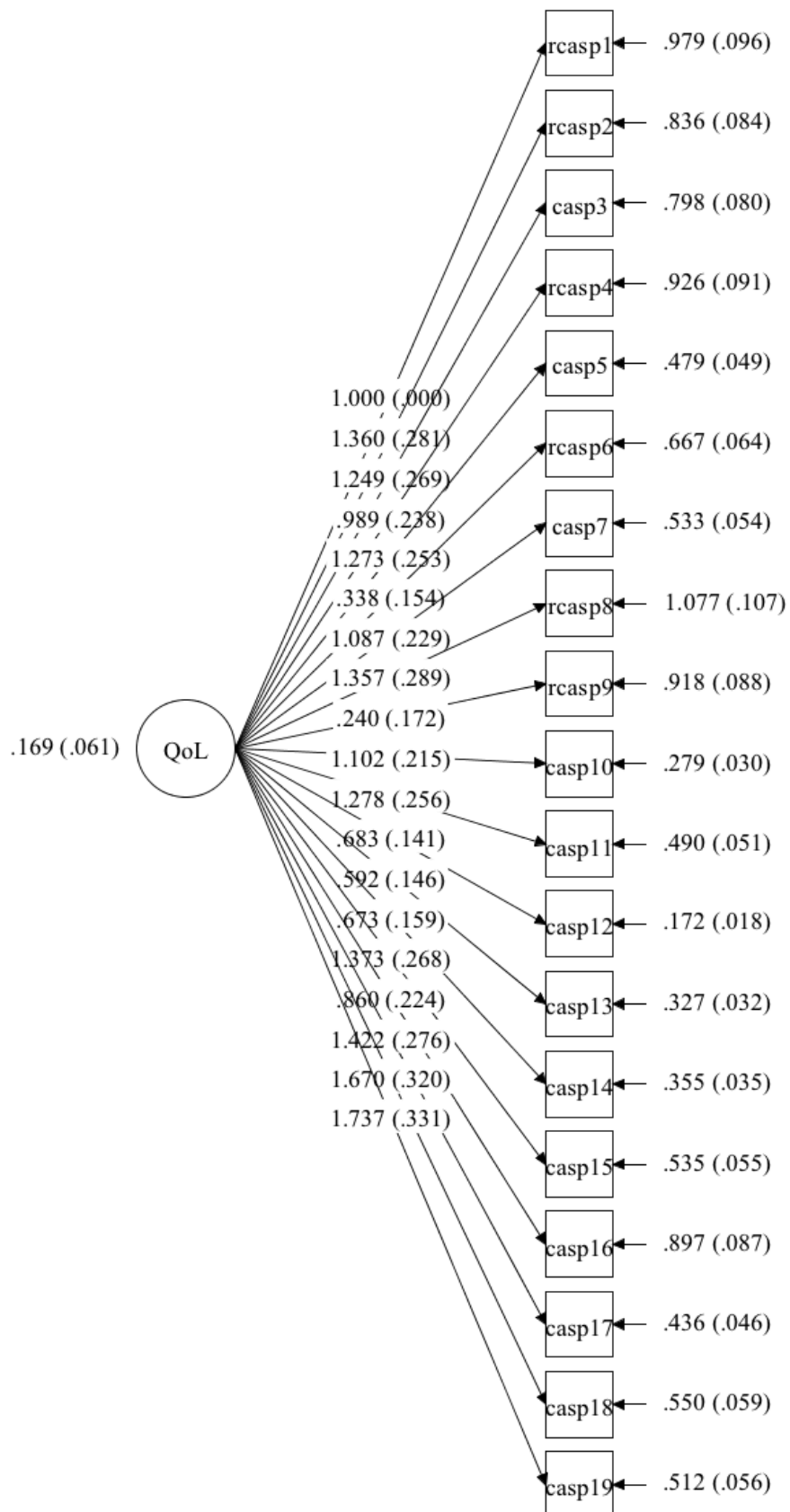


Figure 8.14 CFA Integrated factor loadings for CASP-19

The poor fit meant that further analysis was needed. The scale authors indicated that a second-order model in which the subscales of control, autonomy, self-realisation and pleasure loaded into the quality of life factor, was an adequate fit. Therefore, a second order factor analysis was conducted using integrated data and all items on the CASP-19. This model indicated an improvement upon the first order factor analysis with the SRMR moving to within an acceptable range ( $<.08$ ) but the CFI and RMSEA were again outside of the cut off criteria (Table 8.10).

*Table 8.10 CFA integrated fit indices for second order structure of CASP-19*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>1 Factor</b>	393.67*	148	0.795	.087	.076

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

The subscales loaded onto the latent quality of life factor significantly ( $p < .001$ ) but item 9 did not significantly load onto the autonomy subscale ( $p = .128$ ). Item 9 was removed and the analysis was run again causing the fit indices to improve (Table 8.11). Again, the SRMR improved as did the CFI but the RMSEA worsened slightly. In this model, only the SRMR was within the cut off criteria. The new model, using a second-order factor structure and omitting item 9, was accepted (Figure 8.15).

*Table 8.11 CFA integrated fit indices for second order structure of CASP-19 omitting item 9*

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>1 Factor</b>	354.26*	131	0.81	.088	.074

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

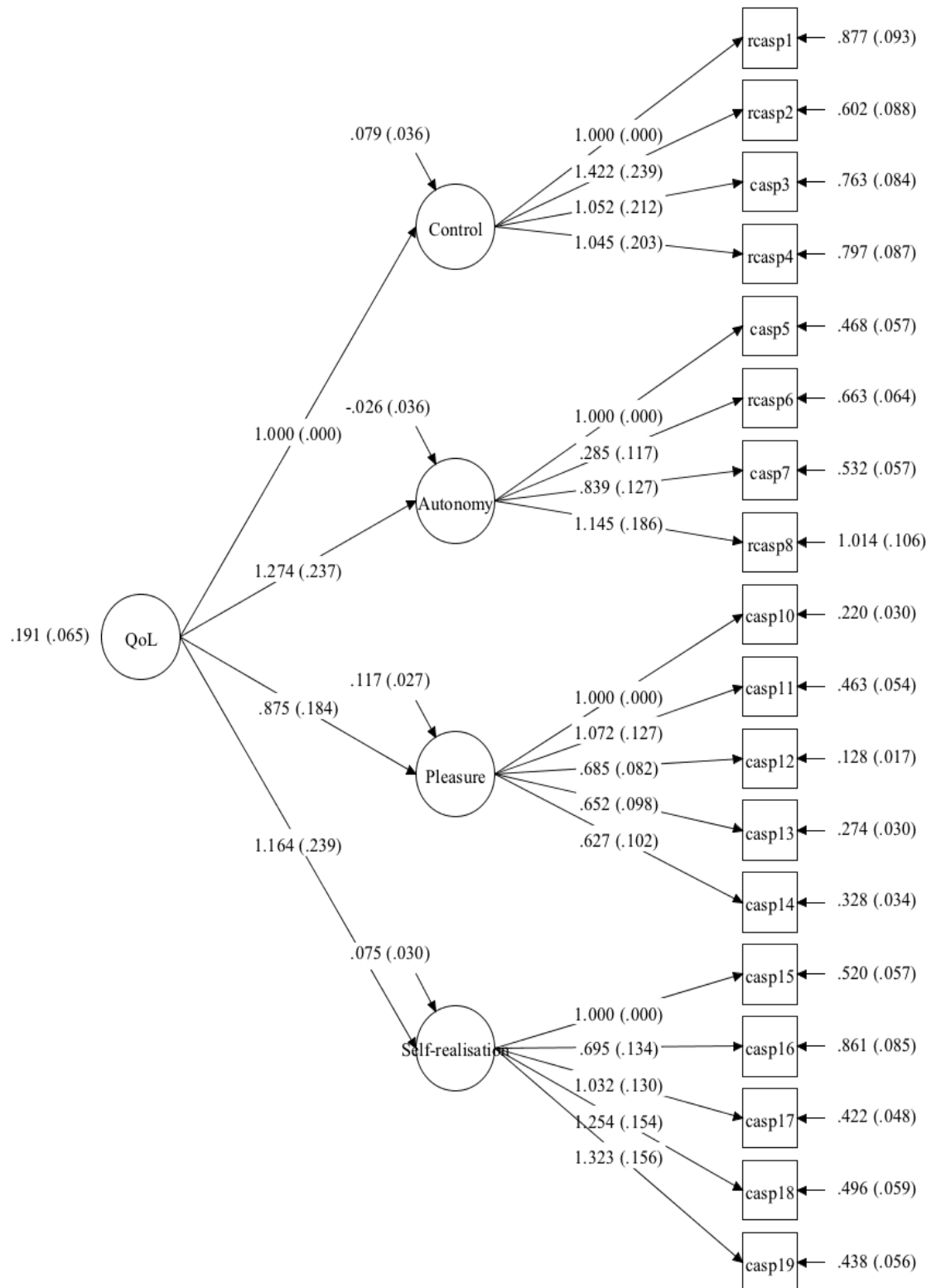


Figure 8.15 CFA Integrated second order factor loadings for CASP-19

## 8.5 Discussion

A two-factor structure was identified for both the PPOM and EID-Q, whilst a one factor structure was identified for the CASP-19. Whilst all three fell at varying points above or below recommended guidelines set for fit indices, all items loaded onto their respective factor. Eigenvalues indicated that measures may have had more factors than anticipated. However, eigenvalues alone should not be used to extract factors. Others (e.g. Cattell, 1966) have noted the usefulness of scree plots to determine the number of values, with a substantial drop indicating in eigenvalues indicating where extraction should stop. However, this assessment is subjective in nature and, therefore, determination of factors should reside on both theory and data evidence using a combination of the approaches mentioned.

### 8.5.1 *The PPOM*

Analysis of the PPOM indicated that both a one-factor and a two-factor solution might be appropriate, as some items loaded onto both factors. This may be attributable to the presence of hope contributing to adaptive recovery from stress (Ong, Edwards, & Bergeman, 2006). However, whilst related, the two are distinct concepts in the literature and consequently it was more appropriate to treat them as such and use a two-factor model, in which the factors were allowed to share covariance. Whilst two items loaded onto both factors, in no instance did an item load onto the incorrect factor, further providing evidence for a two-factor solution.

### 8.5.2 *The EID-Q*

The EFA of the EID-Q indicated that a two-factor solution was most acceptable. However, during the CFA stage model fit was worse than expected and not acceptable so a new model was proposed using a five-factor, second order solution. Subscales were



created and these have been named; Decision making, Activity Engagement, Support Network, Activities of Daily Living and Reciprocity (Appendix 1.7), based upon the items they consisted of and evidence in the qualitative study in Chapter 5. However, it must be acknowledged that for the EID-Q's, second order five factor solution, the CFI fell below the acceptable limit of  $>.9$  and this indicates that the model proposed may not be an adequate fit to the data, limiting the degree to which latent variables can be inferred from the measurement model. However, improvements in the CFI have previously been described as representing adequate progress in model fit. For the EID-Q, the CFI improved from a low of .677 to a high of .821 indicating model improvement and acceptability (Bollen, 1989).

All subscales loaded onto two latent factors entitled Independence and Social Engagement. These two factors shared co-variance, providing evidence for 'Interdependence'. The concept of interdependence is supported in Chapter 6 where, independence and social concepts were discussed in conjunction with each other and terms were often used interchangeably. Independence for people with dementia is often theorised as resting on domains such as self-care, mobility, continence, participation in activities, orientation and environmental change (Woods, 1999). It is suggested that, in addition to these physical domains, people with dementia's belief about the support they receive and their wider engagement in networks and activities also plays a role in whether or not they feel independent. As this measure is subjective, more emphasis is placed on that belief rather than the actual behaviour itself. This is evidenced by both physical and social domains loading onto their latent factors and lends itself to the notion of a 'sense of independence' being more than a satisfaction of physical domains such as self-care.

### **8.5.3 The CASP-19**

Analysis of the CASP-19 in the EFA stage, indicated that the underlying latent factor reported by Hyde, Wiggins, Higgs and Blane (2003), to some degree, remained stable for people with dementia. However, items six and 9 remained problematic, as reported in Chapter 7. Both items, at differing stages, worsened and improved the model. It may be useful to consider the applicability of this item for people with dementia in conjunction with a close examination of item six. Using the second order factor analysis, a small degree of fit was evidenced. Both the CFI, and RMSEA were above and below the acceptable limits of  $>0.9$  and  $<.08$ , whilst the RMSEA fell within the cut off. Again, as with the EID-Q, this indicated that the model proposed here was not an adequate representation of the data, limiting the degree to which one can assign meaning to latent factors within the model.

The CASP-19 has been subject to a number of different factor analyses (e.g. Kim, et al., 2015), each proposing differing items are dropped from the scale. For people with dementia, item 9 (shortage of money prevents me from doing the things I want to do') should be examined further to ensure it holds content validity for people with dementia. Potential reasons for this item not holding as much relevance for people with dementia as older adults generally may be the assumption of complex financial decisions by carers (Tilse, Setterlund, Wilson, & Rosenman, 2005) as people with dementia can sometimes struggle with this (Van Wielingen, Tuokko, Cramer, Mateer, & Hultsch, 2004). However, a more detailed examination is needed before this item is omitted.

### **8.5.4 Methodological Problems and Limitations**

Whilst randomly splitting data into construction and validation halves is best practice for structural equation modelling (SEM), this meant that the number of data points were

substantially reduced at each stage. This may have impacted upon results, making models identified in the EFA stage more difficult to confirm in the CFA stage. Furthermore, sample sizes are known to impact upon the Chi-Squared goodness of fit statistic to the degree that small changes can have a large impact upon results and larger sample sizes are likely to result in the rejection of a model, despite trivial differences. The Chi-Squared goodness of fit should, consequently, always be examined with caution and with reference to other indices. To compensate for significant Chi-Squared statistics, other fit indices were examined. In future, to ensure that the proposed model is the best possible fit for the observed data, further and more large-scale research is needed.

Analysis of the CASP-19 was problematic. Whilst items six and 9 did not load significantly onto the latent quality of life factor at differing stages, removing them significantly worsened the proposed model. This meant that a number of nested models were proposed and each model was tested against that preceding it. Whilst this is standard practice with SEM, it meant that finding the latent quality of life factor was accomplished after numerous preceding models had been computed and discarded.

#### ***8.5.5. Conclusion***

A combination of EFAs and CFAs allowed models to be identified and confirmed for the PPOM, EID-Q and CASP-19. The PPOM was identified as having two factors, the EID-Q five and the CASP-19 one.

## **9. Characteristics and outcomes associated with positive psychology**

### **PART A: Demographic and clinical characteristics**

#### **9.1 Introduction**

The notion that people can use positive concepts or have positive experiences in spite of or as a result of dementia is still rarely discussed in the literature (Patterson & Wolverson, 2016). Previously, positive experiences have sometimes been described within a coping paradigm in which these experiences are an attempt to cope with losses associated with dementia by maintaining a sense of usefulness to others. (Steeman, Godderis, Grypdonck, De Bal, & Dierckx De Casterle, 2007). However, there is a need to explore positive experiences and concepts for people with dementia through alternative lenses.

On a psychometric level, the PPOM, EID-Q and CASP-19 were established as adequate measures. However, psychometric analysis does not provide an insight into the theoretical relationship between positive concepts and people with dementia. The qualitative literature in this area describes how people with dementia experience positive psychology concepts, but it does not evaluate the extent to which this might differ depending on demographic or clinical characteristics. It also does not provide insight as to how these positive concepts may relate on a quantitative level to quality of life and depression. Furthermore, second wave positive psychology emphasises the co-existence of both positive and negative emotion (Fredrickson & Losada, 2005) but the extent to which these can co-exist for people with dementia is yet to be examined. Therefore, there was a need to explore and delineate characteristics that may impact upon positive psychology concepts.

### ***9.1.1 The Effect of Age***

The ‘third age’ in sociology is often defined as life after retirement, in which people pursue expanded leisure activities and is often referred to as a period of self-actualisation (Higgs & Gilleard, 2015) which emerges irrespective of prior socio-economic or biographical details (Featherstone & Hepworth, 1989). As this approach is classed a golden age of ageing, the subsequent stage (fourth age), which people with dementia are sometimes categorised as being in, is often viewed as an age of growing dependence and frailty (Karpf, 2014). However, people who have been diagnosed with dementia may still consider themselves as living in this golden age and a diagnosis of dementia should not affect this. Therefore, age should have no impact on the strength of positive psychology concepts.

### ***9.1.2 The Effect of Gender***

Although unknown for people with dementia, women have been found to typically score higher on strengths such as kindness, love and social intelligence, whilst men score higher on creativity (Linley, et al., 2007). It is, therefore, possible that gender will impact upon positive psychology concepts here.

### ***9.1.3 The Effect of Dementia Sub-Type***

In the quality of life literature, there is no differentiation between participants who have Alzheimer’s and those that have other forms of dementia. Most quality of life measures are developed for use with people who have a diagnosis of dementia rather than specific sub-types and these measures are used successfully (Brod, Stewart, & Sands, 1999). In other cases, measures developed specifically for people with Alzheimer’s disease have been used with people with other types of dementia, with no systematic differences reported (Edelman, Fulton, Kuhn, & Chang, 2005). It is therefore possible that, in the

related field of positive psychology, there would be no systematic differences between dementia subtype and scores on positive psychology measures.

#### ***9.1.4 The Effect of Time Spent Living with Dementia***

The most substantial review of the qualitative literature for positive experiences in people with dementia notes that, often, being diagnosed with dementia has little if no effect on positive experiences (Wolverson, Clarke, & Moniz-Cook, 2016). Furthermore, people with dementia may experience personal growth as a result of the diagnosis, in relation to re-evaluating their sense of identity (Clare, Goater, & Woods, 2006). Whilst issues of articulation may confound the examination of positive experiences in later stage dementia, there is no evidence to suggest that living with dementia for extended periods might impact upon the degree of wellbeing or feelings of hope or resilience.

#### ***9.1.5 The Effect of Cognition***

The Mini Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) was used in the Mindfulness Based Cognitive therapy intervention (MBCT) described in Chapter 9. The qualitative literature suggests that people actively use character strengths throughout the course of dementia (Wolverson, Clarke, & Moniz-Cook, 2016) and therefore differing levels of cognition should not be related to positive psychology measures. However, as cognition and language skills deteriorate, it may be that people with dementia are unable to articulate complex positive psychology strengths as well as less impaired individuals.

#### ***9.1.6 Quality of Life***

The relationship between positive psychology and quality of life is yet to be explored for people with dementia. Whilst a correlation between positive measures was

documented in Chapter 7, there was a need to further explore this relationship. In the positive psychology literature, it has been proposed that the presence of positive psychology emotions or traits (e.g. life satisfaction) can lead to an increase in wellbeing (Seligman & Csikszentmihalyi, 2000) and quality of life (Myers, 2000). In dementia research, there are no quantitative studies of positive psychology and its relationship to quality of life. However, functional independence or the ability to perform activities of daily living has been found to be associated with higher health related quality of life (Anderson, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sørensen, 2004). It is, therefore, possible that this relationship might be extended to a sense of independence as measured in the EID-Q.

### ***9.1.7 Depression***

In Chapter 7, it was suggested that positive psychology might act as in a protective fashion against the development of depressive symptoms based on the association between higher resilience and less depressive symptomology documented in older adults (Wermelinger Ávila, Granero Lucchetti, & Lucchetti, 2016). In the dementia literature, functional impairment is associated with higher depression (Rovner, Broadhead, Spencer, Carson, & Folstein, 1989) but, as yet, there has been no research regarding whether feeling independent may protect against depression or whether or not these states can co-exist.

## **9.2 Aims**

The aim of this chapter was to evaluate the degree to which demographic and clinical characteristics impact upon novel measures and assess the relatedness of quality of life and depression by means of SEM. For Part A of this chapter, the following sub-aims were set:

1. Analyse the impact of differing characteristics on average scores for the PPOM, EID-Q and CASP-19.
2. Assess the degree to which depression can co-exist with positive traits.
3. Assess the ability of the positive measures to predict depressive symptomology and quality of life.
4. Explore the differences between high and low scorers on positive psychology measures.

### **9.3 Methods**

#### ***9.3.1 Design***

A secondary analysis was performed using all data (n =237). Demographic information for participants forming the psychometric study can be found in Chapter 7.

#### ***9.3.2 Additional Outcome Measures***

##### ***9.3.2.1 Mini Mental State Examination (MMSE; Holstein, Folstein & McHugh, 1975)***

The MMSE is a widely used measure of cognition and assesses orientation, attention, recall, language and visual construction. It contains 11 items and possible scores range from zero to 30. It has established psychometric properties and is extensively used in research for people with dementia. Internal consistency has been reported as being between .68 and .96 and test-retest reliability is adequate (reliability coefficients of .80 to .95) (Tombaugh & McIntyre, 1992). A score of 24 or above indicates no cognitive impairment, 18-23 indicates mild cognitive impairment and 0-17 indicates severe cognitive impairment (Folstein, Folstein, & McHugh, 1975).



### ***9.3.3 Data Analysis***

Participant pools were combined with mean imputation and multiple imputation performed, as outlined in Chapter 7. As well as using the continuous variables for all measures, a series of new categorical variables were created using the median to categorise those who scored higher and those that scored lower on the PPOM, CASP-19 and EID-Q.

Demographic and clinical information was then analysed using continuous data and also categorical data (high and low scores) for each of the measures. A further variable was then created, in which participants who scored above the combined median of both the EID-Q and PPOM were grouped and those that scored below the median for both of these measures were grouped.

To assess the relationship between hope, resilience, independence, engagement and demographic or clinical information, a combination of Pearson's R correlation coefficients, t-tests, linear regressions and binary logistic regressions were used. Pearson's R correlations were used as an indication of a correlational relationship between continuous variables and t-tests were used to indicate significant difference between groups using means. Following this, a linear regression was used. A linear regression represents the next step up from a correlation analysis and assesses the degree to which one variable can be predicted from another. Assumptions to be satisfied for a linear regression are (Poole & O'Farrell, 1971):

1. Variables within a model should be continuous.
2. A linear relationship must exist between these two variables.
3. There should be no significant outliers.
4. Observations should be independent of each other.

5. Data should show homoscedasticity.
6. Residual error terms must be approximately normally distributed.

Finally, a binary logistic regression was used using data from the new categorical variables. This is preferable over an ANOVA's and t-tests, which requires continuous dependent variables and can be computed when linear regression assumptions are violated. There are a number of assumptions to be met before a binary logistic regression can be performed. These are:

1. The dependent variable must be dichotomous in nature.
2. There must be no multicollinearity between predictors. Generally, if no correlations are above 0.9, then this assumption is met (Tabachnick & Fidell, 1996).

#### **9.4 Results**

The median of the PPOM was calculated as 50. Therefore, participants scoring below 50 were categorised as 'low scorers' and those who scored above 50 were categorised as 'high scorers' resulting in 118 participants as low scorers and 117 as high scorers. For the EID-Q the median was 83, resulting in 120 participants categorised as low scorers and 117 categorised as high scorers. The CASP-19 had a median of 42 meaning 130 participants were categorised as low scorers and 106 categorised as high scorers. A score of 37 was determined to be the median for the QoL-AD, resulting in 130 categorised as low scorers and 106 categorised as high scorers. Finally, for the GDS the median was three. Therefore, those scoring three or below were categorised as low scorers (n = 124) and those scoring four or above were categorised as high scorers (n = 113).

To assess an overall score for the degree of concepts measured by the PPOM and EID-Q were summed and the median of this overall score was used to split participants into high and low groups. The possible range for this total variable ranged from 0 – 168 with the observed range from 34 – 168. The mean was 128 and median 132. Following the re-categorisation 119 participants were classed as low scorers and 117 as high scorers. Following the re-categorisation of ages, 11 participants fell within the 50 – 60 range, 33 within the 61 – 70 range, 79 within the 71 – 80 range, 65 within the 81 – 90 range and 14 within the 91 – 100 range.

#### ***9.4.1 Participant demographics and clinical characteristics***

A full description of participants can be found in Chapters 8 and 9. The total sample here consisted of 237 participants. Briefly, participants had a mean age of 77.54, were predominantly White British ( $n=209$ ) and married ( $n=151$ ). A large proportion had been diagnosed with Alzheimer's disease ( $n=115$ ) or dementia of mixed aetiology ( $n=50$ ). Most commonly, participants had been living with dementia for under one year ( $n=79$ ).

#### ***9.4.2 The effect of age***

##### ***9.4.2.1 PPOM***

To meet the assumptions of a linear regression model, a Pearson's R correlation coefficient was used and found to be statistically significant ( $r = .137, p = .019$ ).

However, this was not supported upon visual inspection of a scatterplot (Figure 9.1), which indicated that there was little evidence of a linear relationship between age and the PPOM. This violated assumption two and therefore a linear regression was not performed.

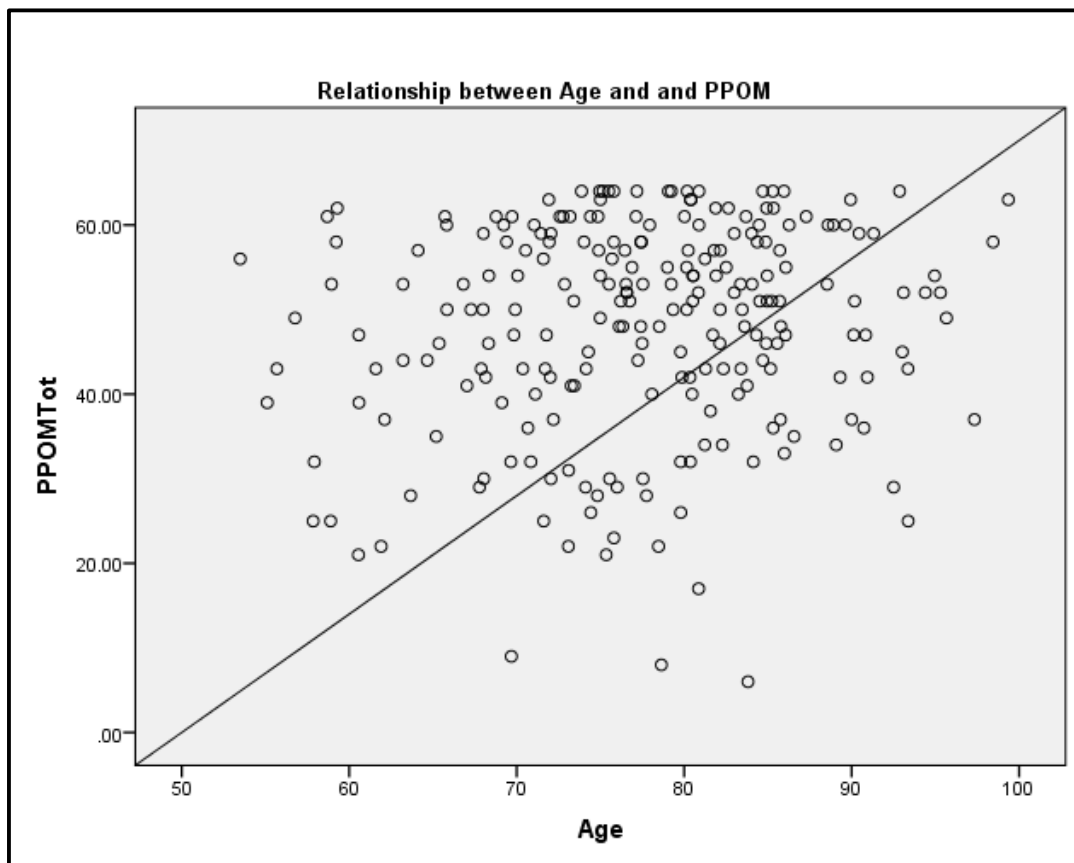


Figure 9.1 Scatterplot of the relationship between age and total scores on the PPOM

Prior to re-categorisation of the ages into age groups and using the categorical data of high and low scorers, a scatter graph indicated little variability between high and low scorer's dependent on age. The binary logistic regression was not significant ( $\chi^2(1) = .966, p = .326$ ), with the model only explaining 0.6% of variance in scores on the PPOM and classified correctly in 54.9% of cases. Following the grouping of ages the model explained 16% of variance and was still not significant ( $\chi^2(4) = 2.512, p = .642$ ).

#### 9.4.2.2 EID-Q

There was no significant correlation between age and the EID-Q ( $r = .07, p = .288$ ).

This meant assumption two of a linear regression model was violated and not

performed. For the EID-Q, the binary logistic regression between age and high and low scorers was again not significant ( $\chi^2(1) = .005, p = .944$ ) with the model accounting for zero variance and correct classification only occurring in 51.1% of cases. After ages were categorised into groups, the new model accounted for 2% variance but this was not significant ( $\chi^2(4) = 2.982, p = .561$ ).

#### 9.4.2.3 Combined PPOM and EID-Q

For the overall variable computed by summing totals on the PPOM and EID-Q, a Pearson's R indicated that age and overall scores were not related ( $r = .106, p = .108$ ). Therefore, a linear regression was not conducted. The binary regression using categorical scores on the overall variable and age as a continuous variable was again not significant ( $\chi^2(1) = .966, p = .326$ ). The model only accounted for 6% variance and correctly classified in 54.9% of cases. Following re-categorisation of ages into age groups, the model accounted for 1.6% of variance, correctly classifying in 55% of cases, but was not significant ( $\chi^2(4) = 2.512, p = .642$ ).

#### 9.4.2.4 CASP-19

The CASP-19 was also not significantly correlated with age ( $r = .037, p = .578$ ), rendering a linear regression redundant. The binary logistic regression model for the CASP-19 was also not significant ( $\chi^2(1) = .015, p = .902$ ), with the model accounting for zero variance and correct classification occurring in 52.4% of cases. After regrouping ages into categories, 1% of variance was explained and the model was not significant ( $\chi^2(4) = 1.545, p = .819$ ).

### 9.4.3 The effect of gender

Frequencies of high and low scorers by gender were assessed for the PPOM, EID-Q and CASP-19 (Table 9.1). Frequencies tables suggested that, for most measures, proportions remained relatively stable, with the exception of the CASP-19 for which it appeared that higher proportions of men scored lower than their female counterparts.

Table 9.1 Frequencies of high and low scorers by gender

	Low scorers ( <i>n</i> )		High scorers ( <i>n</i> )	
	Men	Women	Men	Women
<b>PPOM</b>	62	57	66	52
<b>EID-Q</b>	68	52	60	57
<b>Overall (PPOM + EID-Q)</b>	62	57	66	52
<b>CASP-19</b>	72	58	56	51

#### 9.4.3.1 PPOM

An independent samples t-test indicated that there were no significant differences between average scores on the PPOM and gender ( $t(2098257) = .984, p = .325$ ).

Correlation matrixes indicated that there was no multicollinearity between independent variables but a binary logistic regression indicated that the model only explained 0.3% of variance and was not significant ( $\chi^2(1) = .477, p = .490$ ).

#### 9.4.3.2 EID-Q

Average scores on the EID-Q did not differ depending on gender ( $t(6155362) = -.510, p = .610$ ) and a binary logistic regression resulted in no significant findings ( $\chi^2(1) = .376, p = .540$ ) and explained only 0.2% of variance.

#### 9.4.3.3 Combined PPOM and EID-Q

The combined score of the EID-Q and PPOM did not differ depending on gender ( $t(18535566) = .159, p = .874$ ), either at a continuous level using the mean, or at a

categorical level using the median ( $\chi^2(1) = .477, p = .490$ ). Within this model, gender only accounted 0.3% of variance.

#### 9.4.3.4 CASP-19

There were no significant differences between average scores on the CASP-19 by gender ( $t(1027620) = .512, p = .609$ ). This remained non-significant following a binary logistic regression ( $\chi^2(1) = .151, p = .697$ ), which explained 0.1% of variance.

#### 9.4.4 The effect of dementia sub-type diagnosis

Frequency statistics were requested to examine the proportion of people categorised as high and low scorers, dependent on specific sub-type diagnosis. Largely, proportions of participants appeared to remain consistent across diagnoses. Those with Alzheimer's disease appeared to be more likely to be categorised as high scorers, although this was not the case for the CASP-19 (Tables 9.2 and 9.3).

##### 9.4.4.1 PPOM

After removing those with rare dementias for which there were one reported case for each and cases where no sub-type was reported (leaving  $n = 215$ ), a one-way ANOVA indicated that there was a significant difference between groups ( $F(5,205) = 2.77, p = .019$ ). A post hoc comparison test revealed that there was a significant difference between those diagnosed with vascular dementia ( $M = 43, SE = 2.18$ ) and those diagnosed with Alzheimer's disease ( $M = 49.47, SE = 1.09, p = 0.44$ ) but this was not significant after Tukey post-hoc corrections ( $p = .100$ ). A binary logistic regression was then used to analyse whether variance on the categorised dependent variable (high PPOM score and low PPOM score) could be explained by diagnosis subtype.

Assumptions of binary regressions were met but there was no significant variance

explained by dementia sub-type ( $\chi^2(7) = 9.322, p = .230$ ). Variance explained by diagnosis subtype represented 5.1% and correct classification occurred in 57% of cases.

#### 9.4.4.2 EID-Q

Prior to categorisation of the EID-Q into high and low scorers, a one-way ANOVA indicated that there were no significant differences between groups ( $F(5,206) = 1.645, p = .150$ ). Following categorisation of the dependent variable (EID-Q high scorers and EID-Q low scorers), only 4.8% of variance was explained by dementia sub-type for the EID-Q and this was not significant ( $\chi^2(7) = 8.738, p = .272$ ). Correct classification occurred in 55.3% of cases.

Table 9.2 Frequencies of low scorers by diagnosis

	Low Scorers (n)					
	Alzheimer's	Vascular	Mixed	PRD	FTD	PPA
<b>PPOM</b>	51	25	28	2	4	1
<b>EID-Q</b>	54	24	28	2	3	0
<b>Overall (PPOM + EID-Q)</b>	51	25	28	2	4	1
<b>CASP-19</b>	59	28	29	2	4	1

Table 9.3 Frequencies of high scorers by diagnosis.

	High Scorers (n)						
	Alzheimer's	Vascular	Mixed	PRD	FTD	CVD	PPA
<b>PPOM</b>	64	18	22	1	1	1	0
<b>EID-Q</b>	61	19	22	2	2	0	0
<b>Overall (PPOM + EID-Q)</b>	64	18	22	0	1	1	1
<b>CASP-19</b>	57	15	21	0	1	1	1

PRD: Parkinson's related dementia; FTD: Frontotemporal dementia; PPA: Primary Progressive Aphasia; CVD: Dementia due to cardiovascular disease.

#### 9.4.4.3 Combined PPOM and EID-Q

Overall, a one-way ANOVA indicated that there were significant differences between groups ( $F(5,204) = 2.394, p = .039$ ). However, this was not significant following post-



hoc contrasts ( $p = .068$ ). Only 5.1% of variance was explained by dementia sub-type on the PPOM and EID-Q combined using a binary logistic regression and represented correct identification in 57% of cases. Nevertheless, this was not significant ( $\chi^2(7) = 9.322, p = .230$ ).

#### 9.4.4.4 CASP-19

A one-way ANOVA using total scores on the CASP-19 as the dependent variable and dementia subtype as the independent variable was not significant  $F(5,205) = 2.154, p = .060$  indicating that mean scores on the CASP-19 did not significantly differ by dementia sub-type. The binary logistic regression classified 56.5% of cases correctly, explaining 5.7% of variance. However, again, this was not significant ( $\chi^2(7) = 10.350, p = .170$ ).

#### 9.4.5 The effect of time spent living with dementia

Frequency distributions were examined to assess the number of participants classed as low (Table 9.4) and high scorers (Table 9.5) on each of the measures. Those who were not aware of how long they had been living with dementia were excluded from this analysis leaving a total of  $n = 213$ .

The proportion of participants who were categorised as either high or low scorers appeared to remain largely stable across time post-diagnosis. However, it appeared that participants who had been diagnosed within the last year were more often categorised as low scorers.

*Table 9.4 frequencies of low scorers by time spent living with dementia*

	Low Scorers (n)				
	<1 years	1-2 years	2-3 years	3-4 years	>4 years
<b>PPOM</b>	42	26	16	11	10
<b>EID-Q</b>	41	30	14	12	10

<b>Overall (PPOM + EID-Q)</b>	42	26	16	11	10
<b>CASP-19</b>	46	28	20	11	9

*Table 9.5 Frequencies of high scorers by time spent living with dementia*

	<b>High Scorers (n)</b>				
	<1 years	1-2 years	2-3 years	3-4 years	>4 years
<b>PPOM</b>	37	29	23	11	8
<b>EID-Q</b>	38	25	25	10	8
<b>Overall (PPOM + EID-Q)</b>	37	29	23	11	8
<b>CASP-19</b>	33	27	19	11	9

#### *9.4.5.1 PPOM*

Initially, a one-way ANOVA was used to assess whether there were any differences between the mean PPOM score and time spent living with dementia. No significant differences were found between groups ( $F(4,203) = .459, p = .766$ ). A binary logistic regression using high and low scorers as the dependent variable was also not significant ( $\chi^2(4) = 1.432, p = .839$ ), indicating the time spent living with dementia was not related to categorisation as a high or low scorer on the PPOM. The proposed model only explained 0.9% of variance and correct classification occurred in 53.1% of cases.

#### *9.4.5.2 EID-Q*

A one way ANOVA indicated there was no significant differences across groups and mean scores on the EID-Q ( $F(4,204) = .723, p = .557$ ). A binary logistic regression using high and low scorers as a categorical dependent variable was also not significant ( $\chi^2(4) = 3.975, p = .409$ ), explaining 2.5% of variance. Correct classification occurred in only 54.9% of cases.

#### *9.4.5.3 Combined PPOM and EID-Q*

Using the combined scores of the PPOM and EID-Q, a one-way ANOVA was conducted with time spent living with dementia as the independent variable. This was not significant ( $F(4,202) = .552, p = .698$ ) indicating no differences between groups. The binary logistic regression, using categorical overall scores (high and low) was also not significant ( $\chi^2(4) = 1.432, p = .839$ ). The proposed model explained 0.9% of variance and correct classification occurred in 53.1% of cases.

#### *9.4.5.4 CASP-19*

A one-way ANOVA indicated that there were no significant differences between average scores on the CASP-19 by time spent living with dementia ( $F(4,203) = .070, p = .991$ ). Using categorical high scorers and low scorers on the CASP-19 as a dependent variable, a binary logistic regression indicated that length of time spent living with dementia was not related to high or low scores on the CASP-19 ( $\chi^2(4) = .284, p = .991$ ).

#### ***9.4.6 The effect of cognition***

As the MMSE was only collected in a small scale additional study (see Appendix 2.7), this analysis could only be conducted with a small sample ( $n = 21$ ). Multiple imputation was not used for this section as this would involve imputing 216 MMSE total scores, using 21 data points, and would not be an accurate representation of the data. Mean MMSE scores were 24.43 ( $SD = 3.34$ ) and the observed range was 18-29.

#### 9.4.6.1 PPOM

The PPOM was not significantly correlated with MMSE totals ( $r = .116, p = .657$ ), rendering a linear regression redundant. A binary logistic regression using categorical variables for the PPOM, was also not significant ( $\chi^2(1) = 1.958, p < .162$ ).

#### 9.4.6.2 EID-Q

The EID-Q was not significantly correlated with MMSE totals ( $r = -.110, p = .673$ ) and, therefore, a linear regression was not performed. A binary logistic regression was also not significant ( $\chi^2(1) = .953, p < .329$ ), with the proposed model only explaining 6% of variance.

#### 9.4.6.3 Combined PPOM and EID-Q

Again, scores on the PPOM and EID-Q combined were not significantly correlated with MMSE scores ( $r = .013, p = .962$ ) and, as neither the PPOM nor EID-Q were significantly related using categorical data, a binary logistic regression was not conducted.

#### 9.4.6.4 CASP-19

A Pearson's R correlation coefficient indicated that MMSE scores were not correlated with the CASP-19 ( $r = .237, p = .377$ ), rendering a linear regression redundant. Furthermore, high levels of missing data on the CASP-19 for participants who had completed the MMSE also meant that a meaningfulness analysis could not be conducted.

#### 9.4.7 *Quality of Life as a predictor*

In the current study, 130 participants were categorised as low scorers and 107 were categorised as high scorers. Assumptions of linear regression and binary logistic regression were met for each measure included in the analysis. Participants who scored low on the QoL-AD and high on positive measures were examined (Table 9.6)

*Table 9.6 Participants categorised as low scorers on QoL-AD and high scorers on positive measures*

	<b>PPOM</b>	<b>EID-Q</b>	<b>PPOM + EID-Q</b>	<b>CASP-19</b>
<b>Frequency (n)</b>	36	36	36	27

##### 9.4.7.1 *PPOM*

A Pearson's R correlation was previously conducted in Chapter 7, during which the PPOM was found to be significantly positively correlated with the QoL-AD ( $r = .596, p < .001$ ). To further examine this relationship a linear regression was performed on uncategorised data using the PPOM as a dependent variable and the QoL-AD as an independent variable, followed by a binary logistic regression for categorical data. The linear regression indicated that it was possible to significantly predict scores on the PPOM from scores on the QoL-AD ( $R^2 = .383, F(1,228) = 141.45, p < .001$ ). The binary logistic regression was also significant ( $\chi^2(1) = 53.282, p < .001$ ) with the model explaining 26.8% of variance and correct classification occurring in 73% of cases.

##### 9.4.7.2 *EID-Q*

In Chapter 7, a Pearson's R correlation indicated a statistically significant relationship between the EID-Q and the QoL-AD ( $r = .704, p < .001$ ). To further examine this relationship, a linear regression was conducted to establish whether the scores on the EID-Q could be predicted from scores on the QoL-AD. The linear regression was

significant ( $R^2 = .489$ ,  $F(1,229) = 219.03$ ,  $p < .001$ ). Following categorisation into high and low scorers, the model explained 26.9% of variation was correct classification occurred in 73% of cases. The binary logistic was significant, indicating that the degree to which participants were classified as high or low scorers on the QoL-AD could be predicted from their classification on the EID-Q ( $\chi^2(1) = 53.282$ ,  $p < .001$ ).

#### 9.4.7.3 Combined PPOM and EID-Q

Overall scores for the PPOM and EID-Q were not calculated in the main psychometric chapter (Chapter 7). Therefore, a Pearson's R was conducted and a significant positive correlation was observed between the overall scores and the QoL-AD ( $r = .692$ ,  $p < .001$ ). A linear regression identified with the combined PPOM and EID-Q as the dependent variable and the QoL-AD as the independent variable was significant ( $R^2 = .508$ ,  $F(1,227) = 233.97$ ,  $p < .001$ ). Using categorised variables (high versus low), a binary logistic regression was performed and found to explain 26.9% of variance. This was significant ( $\chi^2(1) = 53.282$ ,  $p < .001$ ) and correct classification occurred in 73% of cases.

#### 9.4.7.4 CASP-19

A Pearson's R correlation calculated in Chapter 7 indicated that there was a statistically significant positive correlation between the CASP-19 and the QoL-AD ( $r = .705$ ,  $p < .001$ ). A linear regression to examine whether the QoL-AD could predict the CASP-19 was significant ( $R^2 = .525$ ,  $F(1,228) = 251.617$ ,  $p < .001$ ) and a binary logistic regression using categorised totals was also significant ( $\chi^2(1) = 61.854$ ,  $p < .001$ ). The model explained 30.7% of variance and correct classification occurred in 75% of cases.

#### 9.4.8 Depression as a Predictor

Participants who scored above the median on the GDS for the current study consisted of 113 participants and were categorised as high scorers, whilst 124 scored below the median and were categorised as low scorers. A small proportion of participants indicated the presence of both depression and high scores on all measures (Table 9.7)

*Table 9.7 Participants categorised as both high scorers on GDS and positive measures*

	PPOM	EID-Q	PPOM + EID-Q	CASP-19
Frequency ( <i>n</i> )	24	28	24	22

##### 9.4.8.1 PPOM

A Pearson's R correlation indicated a statistically significant correlation between the PPOM and GDS in Chapter 7 ( $r = -.669, p < .001$ ). A linear regression indicated that the GDS could significantly predict the PPOM ( $R^2 = .383, F(1,228) = 141.45, p < .001$ ) and a binary logistic regression using categorised data indicated this also ( $\chi^2(1) = 58.123, p < .001$ ). The model explained 29% of variance and correct classification occurred in 74.3% of cases.

##### 9.4.8.2 EID-Q

In Chapter 7, a Pearson's R correlation suggested a statistically significant correlation between the EID-Q and GDS ( $r = -.693, p < .001$ ). Using a linear regression, the EID-Q could be significantly predicted using the GDS ( $R^2 = .447, F(1,211) = 170.33, p < .001$ ) and this was consistent using categorical data (high versus low) on both the GDS and EID-Q ( $\chi^2(1) = 42.545, p < .001$ ).

#### 9.4.8.3 Combined PPOM and EID-Q

As no overall score was calculated in Chapter 7, an additional Pearson's R was performed to detect a relationship between the combined PPOM and EID-Q variable and depression and found to be significant ( $r = -.733, p < .001$ ). A linear regression performed to assess whether the combined PPOM and EID-Q could be predicted using the GDS was also significant ( $R^2 = .526, F(1,210) = 232.857, p < .001$ ). Following this, a binary logistic regression was conducted to examine the relationship between the categorical variables for both the GDS and the overall variable. This was also significant ( $\chi^2(1) = 58.12, p < .001$ ), suggesting that high and low scorers on the GDS significantly predicted classification on the overall variable. This model explained 29% of variance and correctly classified in 74.3% of cases.

#### 9.4.8.4 CASP-19

There was a significant negative correlation between the CASP-19 and GDS in Chapter 7 ( $r = -.739, p < .001$ ). A linear regression was used to assess whether the CASP-19 could be significantly predicted using the GDS and this was found to be significant ( $R^2 = .551, F(1,212) = 260.22, p < .001$ ). A binary logistic regression using categorical variables for both the CASP-19 and GDS (high versus low) was also significant ( $\chi^2(1) = 45.361, p < .001$ ), with the model explaining 23.2% of variance and correct classification occurring for 71.3% of cases.

### 9.4.9 Quality of Life and Depression as joint predictors

#### 9.4.9.1 PPOM

A binary logistic regression using both the QoL-AD and the GDS as independent variables and the PPOM as the dependent variable was significant ( $\chi^2(1) = 78.663, p < .001$ ), indicating that the PPOM could be predicted from both quality of life and



depression. The model explained 48.5% of variance and correct classification occurred in 82.2% of cases.

#### *9.4.9.2 EID-Q*

For the EID-Q, a binary logistic regression was significant ( $\chi^2(1) = 67.892, p < .001$ ), accounting for 43.1% of variance on the EID-Q with the QoL-AD and GDS as predictors. The model correctly classified results on the EID-Q in 79.9% of cases.

#### *9.4.9.3 Combined PPOM and EID-Q*

Using the combined categorical variables of PPOM and the EID-Q as the dependent variable and the QoL-AD and GDS as predictors, a binary logistic regression explained 48.5% of variance, with correct classification occurring in 82.2% of cases. This was significant ( $\chi^2(1) = 78.663, p < .001$ ).

#### *9.4.9.4 CASP-19*

A binary logistic regression in which the CASP-19 was the dependent variable and the GDS and QoL-AD were independent variables explained 46.7% of variance and was significant ( $\chi^2(1) = 74.966, p < .001$ ). Correct classification of the CASP-19 occurred in 81.6% of cases.

## **PART B: Path analysis of outcomes**

### **9.5 Introduction**

Path analysis is a form of Structural Equation Modelling (SEM) that extends confirmatory or exploratory approaches to factor structure (Chapter 8) by adding pathways between multiple factors and can be thought of as multiple regression models that use several regression equations (Wright, 1934). It is a method used to test theoretical models that depict relations amongst variables but not a causal modelling technique (Schumacker & Lomax, 2016). Diagrams of path analyses consist of variables usually denoted by rectangles, factors or latent constructs denoted by ovals, causal relationships denoted by single headed arrows and correlations between variables denoted by double headed arrows. Variable error is represented by 'Err' followed by the name of the variable and factor loadings are denoted by ' $\beta$ '. To extend a CFA model, paths are added between factors and can be either directional or non-directional. Path analyses are, therefore, suitable methods for assessing underlying and theoretically based measurement models of multiple variables.

#### ***9.5.1 Flourishing***

Flourishing is usually characterised by a person's ability to live well and achieve an optimal level of functioning, characterised by positive relationships, positive emotions, resilience, mastery and growth (Fredrickson & Losada, 2005). However, an 'optimal level of functioning' cannot be considered in isolation, and does not necessarily mean a denial of negative emotions. Rather, it can be considered a unique attribute that may differ depending on the person. For example, an individual with dementia's optimal level of functioning may differ from that of a young adult. In the context of independence, the EID-Q may be an adequate tool to detect mastery of an environment. Furthermore, in the context of social engagement, which includes themes of reciprocity,

connectedness and participation, the EID-Q may detect positive relationships, an area that has been relatively neglected in the literature to date (Stirling, 2016). As a measure of resilience and hope, the PPOM may indicate positive emotions that contribute to flourishing. Whilst both are under researched for people with dementia, evidence indicates that hope and resilience encourage people to live well. In particular, resilience has been described as consisting of a myriad of positive attributes including acceptance, positive attitude and optimism, active engagement and social engagement (Harris & Keady, 2008). For hope, the social environment may be hold important challenges. It has been suggested that hope cannot be maintained by isolated individuals and requires on-going, positive social interactions (Elliot, 2005). However, older adults with dementia can face stigma, disempowerment and malignant social environments (Swaffer, 2014), which may lead to social isolation. It is therefore, theoretically likely that scores on the PPOM and EID-Q may share co-variance.

### ***9.5.2 Flourishing and Quality of Life***

Factors including cognition, behavioural and psychological symptoms and insight have been theorised as impacting upon quality of life. However, the observed relationship can be varied. A substantial review identified little evidence for the aforementioned factors having a significant impact on quality of life and noted that the relationship varied depending on the report style; carers were consistently more likely to rate a person with dementia as having a lower quality of life (Banerjee, et al., 2009). It is therefore necessary to examine other variables that may impact upon quality of life. One such variable may be ‘flourishing’ discussed earlier as the inter-relatedness of positive psychology principles and quality of life has yet to be explored for people with dementia.

### **9.5.3 Depression**

Whilst the relationship between factors including cognition and quality of life is ambiguous, depression has been consistently found to influence ratings of quality of life (Banerjee, et al., 2009). In the mild to moderate stage people with dementia, who also have depression, consistently report a lower quality of life (Phinney, 2016). However, currently there is no consensus as to the causal relationship between these factors. It may be that depression influences quality of life ratings or that quality of life ratings influence depression.

## **9.6 Aims**

For Part B of this chapter, aims were:

1. Explore pathways between the PPOM, EID-Q, GDS and QoL-AD.
2. Build a model supported by data that examines pathways between variables.

## **9.7 Methods**

SEM techniques rely on several steps: model specification, model identification, model estimation and an evaluation of model fit. Model specification entails specifying variables and pathways to be used in the model. Relations between variables are also specified as non-directional or directional, with non-directional referring to co-variance between variables and directional referring to regression coefficients. The relation between variables can either be fixed or free and unspecified assumptions are set at zero. Model identification involves the examination of known parameters to ensure that an adequate number are included in order to generate appropriate results. Model fit is then evaluated by use of chi-squared differences tests, one incremental fit index (CFI), the SRMR and the RMSEA. Furthermore, the theoretical underpinning of the model and

fit of the model to observed data is examined. There are two assumptions that need to be satisfied before a path analysis can be conducted. Firstly, it is assumed that the sample size is adequate. Whilst this is generally determined by the complexity of the model, an average of 5 - 10 cases per parameter to be estimated is usually considered sufficient (Bentler & Chou, 1987). Secondly, it is assumed that there is no multicollinearity between variables (Schumacker, 2015).

To test competing models of data, path analyses move from an independent model in which no variables are related to a saturated model, in which every variable in the data set is theoretically related. To move from independent to saturated, pathways were added to the values of model parameters. At each stage, a chi-squared differences test was performed to deduce whether the pathways added were significantly improving the model. To calculate this, chi-squared of model A (complex) was subtracted from model B (independent), as were the degrees of freedom, giving a chi-squared difference test. A significant chi-squared differences test denotes an improvement of the model to fit the data, alongside one incremental fit index (CFI), the SRMR and the RMSEA. Pathways are usually based on theoretical knowledge and research.

#### ***9.7.1 Pathway 1 – ‘Flourishing’: A Relationship between the EID-Q and PPOM***

To examine whether the EID-Q and PPOM were related, a co-variance pathway was added between the underlying factors of the PPOM and EID-Q and model fit was examined to determine whether this increased the ‘goodness’ of the model to fit the data.

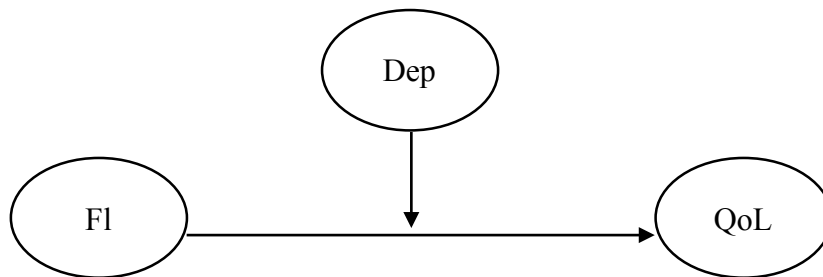
### ***9.7.2 Pathway 2 – Flourishing as a Contributor to Quality of Life***

For the second pathway, quality of life was regressed onto the ‘flourishing’ factor to determine whether flourishing had an effect on the subjective experience of quality of life. A chi-squared test and other model fit evaluations were then performed to examine how good the model was.

### ***9.7.3 Pathway 3 – The Moderating Effect of Depression***

A moderator analysis of depression was explored between the ‘flourishing’ factor and quality of life and a chi-squared differences test was performed (Figure 9.2).

Moderators are variables that influence the strength of a relationship between two separate variables.



*Figure 9.2 Moderator analysis of depression*

## **9.8 Results**

### ***9.8.1 Pathway 1 - Flourishing***

The baseline model in Mplus consisted of the factor structure for the PPOM and EID-Q identified in Chapter 8 but with no correlation or co-variance between these factors (Table 9.8). This acted as a comparison as models become more complex to determine whether adding pathways was significantly improving the model or not.

Table 9.8 Path analysis baseline fit indices for 'flourishing' factor

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
No covariance	1720.51*	811	.82	.071	.07

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

A covariance assessment between the PPOM and EID-Q indicated some co-variance ( $r = 0.43, p < .001$ ) and fit indices remained the same. The PPOM and EID-Q were then loaded onto the latent 'flourishing' factor. The resilience and hope subscale on the PPOM and EID-Q second order, five factor solution significantly loaded onto the 'flourishing' factor ( $r = 1.08, r = 1.16, r = 1, r = 1.3$  all  $p < .001$ ) (Figure 9.3). A chi-squared difference test between models was significant, indicating the model was a better fit to data than the baseline model.

### 9.8.2 Pathway 2 Flourishing as a Contributor to Quality of Life

Fit indices from the above flourishing pathway were used as a baseline model for comparison. The total from the QoL-AD was then regressed onto the flourishing factor to determine whether flourishing was a contributing factor to quality of life. The regression co-efficient was significant ( $r = 9.356, p < .001$ ) (Figure 9.4) and the chi-squared difference test was significant indicating that this model was an improvement on a model in which there was no relationship between flourishing and quality of life. Furthermore, the SRMR improved from .07 to .068 and the RMSEA improved from .071 to .07 suggesting better fit.

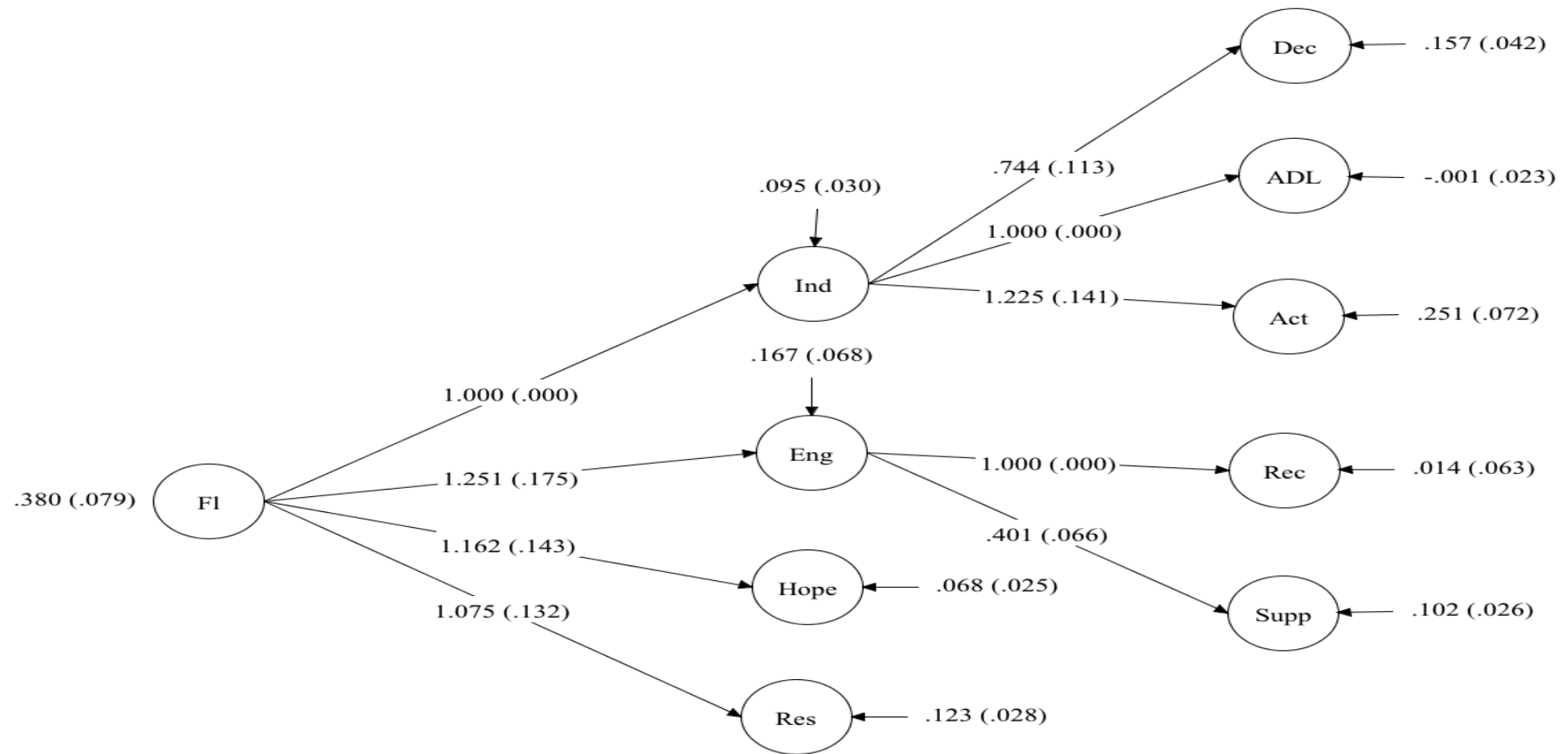


Figure 9.3 Factor loadings for latent flourishing factor



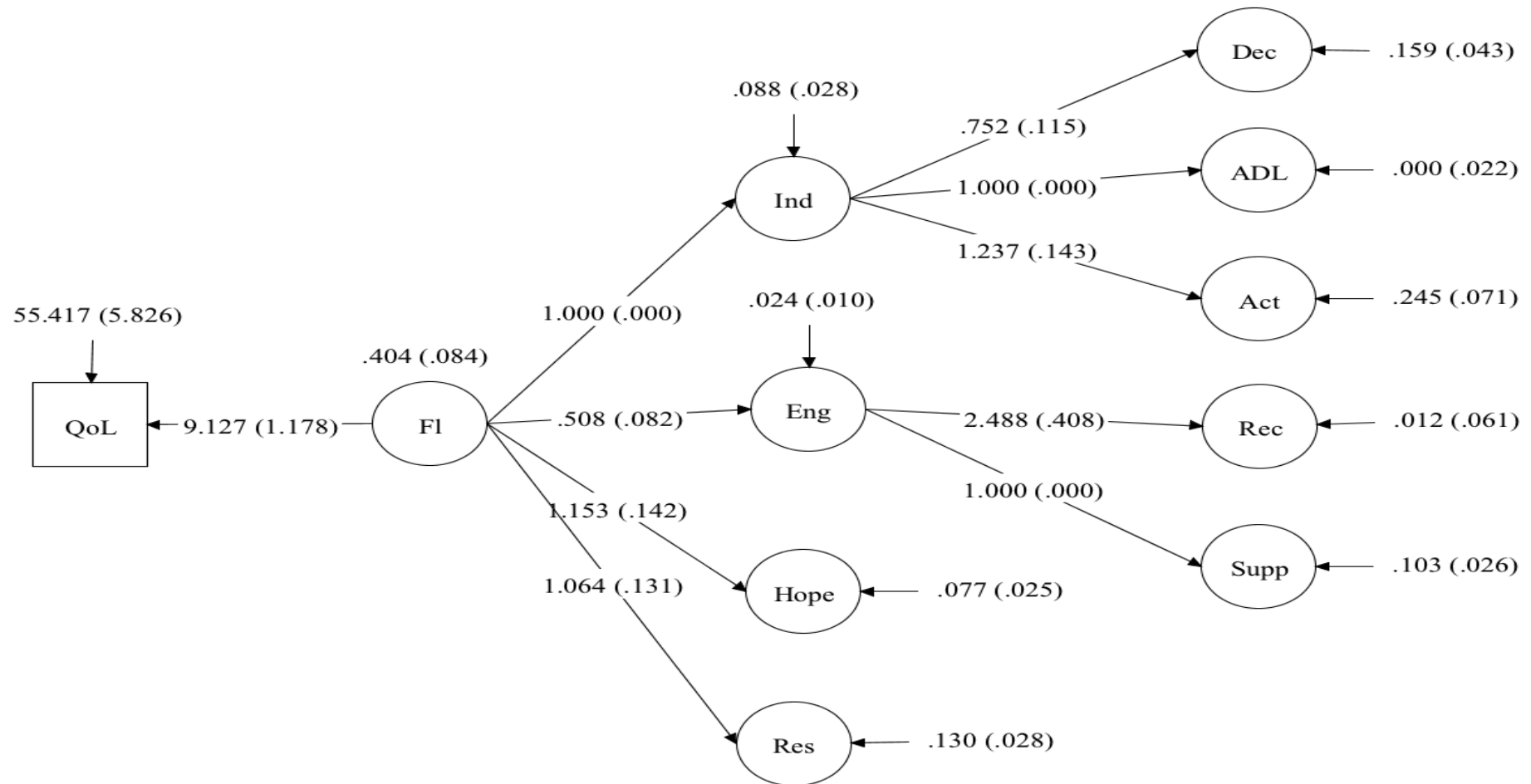


Figure 9.4 Quality of life regressed onto flourishing factor

### 9.8.3 Pathway 3 – The Moderating Effect of Depression

Both flourishing and the GDS total scores were regressed onto quality of life in Mplus. Whilst both significantly loaded onto quality of life ( $r = -.957, p < .001$ ), the model fit worsened (Table 9.9) suggesting this was not a better fit to data than previously established. Therefore, the moderating effect of depression on quality of life was not supported here.

Table 9.9 Moderator analysis of depression

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>Moderator</b>	1935.44*	895	.80	.072	.103

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

However, the relationship between depressive symptomology, the PPOM and EID-Q may be more complex. To determine whether depression impacted on the measures in the first instance, the GDS was regressed onto the factor structures for the PPOM and EID-Q and was allowed to co-vary with the QoL-AD. This significantly improved the model (Table 9.10) and all loadings were significant ( $p < .001$ ) with the exception of the resilience subscale on the PPOM ( $p = .379$ ) (Figure 9.11).

Table 9.10 Regression analysis of depression on positive measures

	$\chi^2$	<i>df</i>	CFI	RMSEA	SRMR
<b>Regression</b>	1859.95*	889	.814	.070	.068

$\chi^2$ = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

\*statistically significant at  $p < .001$ .

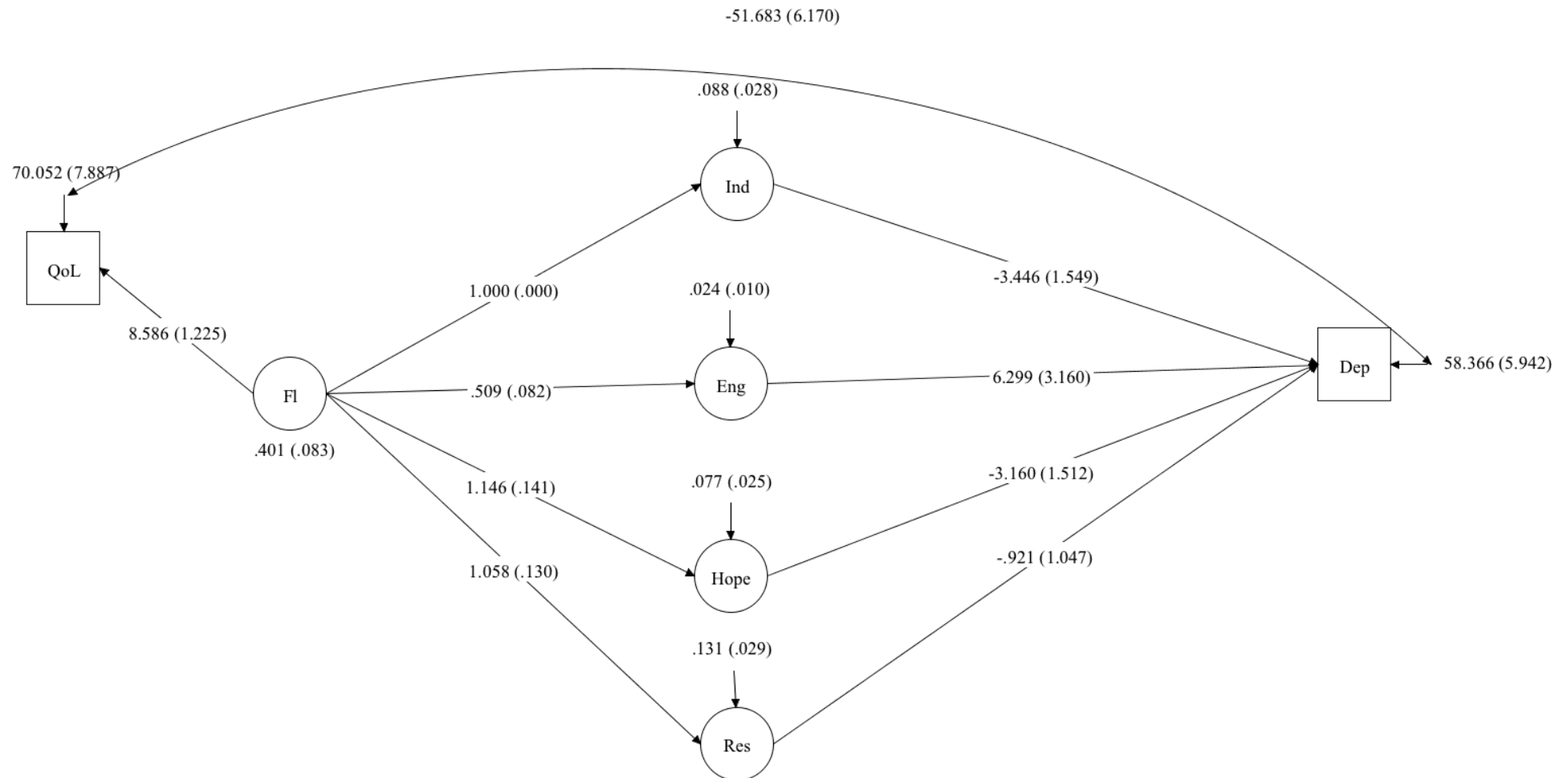


Figure 9.5 Factor loadings for regression analysis of depression

## 9.9 Discussion

Differences in demographic information did not impact upon the PPOM, EID-Q or CASP-19. Age, gender, sub-type of dementia diagnosis and time spent living with dementia were found to not influence the degree to which people reported positive concepts and this was consistent using continuous and categorical data.

Much of the qualitative literature suggests that dementia impacts upon every aspect of a person's life and often in a negative way. Examples include explaining the response to a diagnosis through a grief framework (Robinson, Clare, & Evans, 2005) or the diagnosis resulting in an emotional crisis (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). This negative response is not supported in the current findings as results remained stable, despite individual differences including the length of time spent living with dementia.

However, a person with dementia's sense of self and identity is often largely preserved and unaffected by dementia (Caddell & Clare, 2010) and it may be that these positive concepts are ingrained in identity or selfhood. Indeed, it is often suggested that the presence of positive psychology concepts contribute to a development and enhancement of identity and selfhood (Christopher & Hickinbottom, 2008) so it is not surprising that findings here remained unchanged despite differing characteristics that may impact upon an ability to live well with dementia.

Quality of life and depression, on the other hand, were very closely linked to positive psychology concepts. Quality of life and depression were significant predictors of the PPOM, EID-Q and CASP-19. Both of these are well established as valuable outcomes in research and practice, with quality of life measures systematically included in a number of psychosocial research programmes (e.g. Orrell, et al., 2017; Wenborn, et al.,

2016; Whitaker, et al., 2014). Based on evidence here, it is reasonable to suggest that positive concepts may impact upon these well-established outcomes and further work is needed to explore whether it is possible to enhance quality of life and reduce depression by intervening upon emotions and characteristics that fall under the branch of positive psychology.

Evidence was found for the underlying ‘flourishing’ factor between the PPOM and EID-Q, suggesting that combined high scores on both measures reflect a harmonisation between a person’s sense of self and their social environment and optimal functioning. However, depression as a moderator between flourishing and quality of life was not supported here. This may mean that the relationship between these concepts is more complex than anticipated and, whilst correlated, high scores on positive measures do not equate to low scores on depression measures and vice versa. Furthermore, these differences may be attributable to individual differences in need for participants. For example, some participants may feel they need more of a supportive social network than others and this may contribute more to their wellbeing than feelings of hope or resilience.

### ***9.9.1 Methodological problems and limitations***

Whilst evidence for the stability of positive psychology concepts has been documented here, it was not possible to draw comparisons between those with dementia and those without. However, the definitions garnered and the qualitative study used within Chapters 1-6 were specifically tailored to people with dementia, on the theoretical basis that they may view or interpret positive psychology differently to older people without dementia. Such a comparison using the measures here would, therefore, not be an accurate representation.

Furthermore, it was not possible to explore whether receiving a diagnosis of dementia impacted upon PPOM, EID-Q and CASP-19. It may be that the initial receiving of a diagnosis impacts upon these measures, before people with dementia are able to re-orientate and acclimatise. However, by documenting that each remained stable across different time periods of living with dementia (<1 year, 1-2 years, 3-4 years, >4 years), it was theorised that dementia also does not affect positive psychology concepts.

### ***9.9.2 Conclusion***

The PPOM, EID-Q and CASP-19 did not differ depending on demographic details such as age, gender and time spent living with dementia. Evidence suggested an underlying ‘flourishing’ factor, combining the PPOM and EID-Q and that quality of life and depression were closely related to the measures here. The relationship between depression and this flourishing factor was more complex and did not satisfy the criteria for a moderator.

## 10. Discussion

### 10.1 Overview

This thesis documents the first research to quantitatively assess positive psychology concepts for people with dementia. This innovative research employed a robust and iterative methodology including literature reviews, consultations, a qualitative study, psychometric evaluations and structural equation modelling. Furthermore, development was participant led, meaning that measures developed were selected for their importance to people with dementia, as identified in Chapters 4 and 5. This enabled the development of measures that reflected people with dementia's definitions and experiences of positive psychology and addresses the gap identified in Chapter 2 where generic measures were adopted for use with this population.

#### *10.1.1 The Positive Psychology Outcome Measure (PPOM)*

The Positive Psychology Outcome Measure (PPOM) consists of two subscales: hope and resilience. Hope and resilience were identified in Chapter 4 as important concepts for people living with dementia with hope appearing generalised and present on a day-to-day basis and resilience appearing as a form of resistance to not just dementia but to other health problems also. The Herth Hope Index (HHI; Herth 1992) was found to have adequate psychometric properties in Chapter 2 and was adapted using procedures in Chapters 4 and 5. This was combined with a developed resilience scale, which drew on prominent measures in the literature (e.g. the Connor-Davidson Resilience Scale; Connor & Davidson, 2003) and was developed in Chapters 4 and 5. The PPOM was subject to a pilot, in which it became apparent that future-oriented questions on the hope subscale were problematic for older adults with dementia. Following this, the PPOM was subject to a larger scale study and an in-depth psychometric analysis. Results

indicated good psychometric properties and evidence emerged for a two-factor solution during a factor analysis. Results from the characteristics and structural equation modelling chapter indicated that neither gender, age, sub-type of dementia or time spent living with dementia impacted upon the levels of hope and resilience felt by participants but a complex relationship between hope, resilience, quality of life and depressive symptomology emerged.

### ***10.1.2 The Engagement and Independence in Dementia Questionnaire (EID-Q)***

The EID-Q was developed during the qualitative study in Chapter 5 based on literature reviews and consultations with people with dementia. During the qualitative study, independence emerged as a complex and multifaceted concept. Discussions around independence illustrated its close relationship with social concepts including reciprocity and engagement. This led to the theory of a concept entitled ‘interdependence’ in which participants worked in collaboration with their network to maintain a level of independence that they were desirous of and were comfortable with. The EID-Q was piloted successfully and two items were dropped to improve internal consistency. Using a second order factor analysis (Chapter 8), evidence emerged for the two factors ‘sense of independence and ‘social engagement’. These factors shared covariance providing evidence for ‘interdependence’ and significantly predicted quality of life (Chapter 9). Demographic information such as age, gender and time spent living with dementia did not impact upon levels of interdependence, suggesting stability of the concept across participants. As with the PPOM, sensitivity to change could not be established in the current research.



### ***10.1.3 The Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19)***

The CASP-19 was identified in Chapter 3 as a second order quality of life scale.

Developed using humanist psychology principles, the CASP-19 views quality of life as the satisfaction of the aforementioned four domains. Developed in older adults, it was subject to a psychometric evaluation for people living with dementia. Throughout the course of validation, problems emerged with the autonomy subscale both in the pilot (Chapter 6) and in the main psychometric study (Chapter 7). The internal consistency fell below the acceptable limit for a Cronbach's alpha and, at differing stages, worsened or improved the proposed model in the factor analyses (Chapter 8). Evidence emerged for the same underlying quality of life factor structure reported by the original authors and, as expected, quality of life was a significant predictor of the CASP-19. However, it was not related to age, gender, dementia sub-type diagnosis or time spent living with dementia, suggesting these details do not impact upon quality of life as measured by CASP-19. As with both the PPOM and EID-Q, the CASP-19's responsiveness to change could not be evaluated here.

## **10.2 Findings in the Context of the Literature and Theoretical Implications**

The ability of people with dementia to retain and use character strengths has been documented to some degree in the qualitative literature. Whilst this approach is just beginning to gain traction, further research is needed to operationalise other positive concepts for people with dementia and ensure that they are assessed both qualitatively and quantitatively. This research represents a first step in quantitatively assessing positive psychology for people with dementia.

### ***10.2.1 Models of old age, dementia and positive psychology***

#### ***10.2.1.1 Disengagement Theory and Successful Ageing***

Chapter 1 illustrated the traditional psychology of old age and dementia as one of decline and despondency. Disengagement theory characterises old age as that of withdrawal, resulting in decreased interaction between the ageing person and those in their social network. This was not supported in the current research. Chapter 5 illustrated the ways in which people remain engaged with those around them, often desiring more contact with close family and friends. Furthermore, participants consistently explored their experiences of hope and resilience, noting its importance in day-to-day life.

In relation to this, the research here illustrates why successful ageing has gained such controversy in the literature. Successful ageing was defined in Chapter 1 as consisting of avoiding disease and disability, high cognitive and physical function and engagement with life (Rowe & Kahn, 1997). In contradiction to this, participants here reported engagement with those around them, despite lower levels of cognition than older adults without dementia and scores on quality of life measures were relatively high.

Furthermore, successful ageing does not account for the individual states or traits that contribute to wellbeing, with no exploration of how successful ageing contributes to wellbeing. The combined PPOM and EID-Q scores entitled ‘flourishing’ in Chapter 10 (Section B) were significantly related to quality of life and, therefore, provide evidence that positive psychology concepts hold more significance for the understanding of wellbeing for people with dementia than successful ageing.

### *10.2.1.2 Positive Emotion, Engagement, Relationships, Meaning, Accomplishment (PERMA)*

The combination of the PPOM and EID-Q bears resemblance to the PERMA model, which suggests that the interaction between positive emotion, engagement with activity, positive relationships, meaning and accomplishment results in wellbeing (Seligman, 2011). Like the PERMA model, the combination of the PPOM and EID-Q treats wellbeing or flourishing as the interplay between high levels of individual concepts such as hope and resilience and feelings of independence and engagement with a social network. This further provides evidence for the role of positive concepts contributing to wellbeing for people living with dementia.

### *10.2.1.3 Hierarchical map of concepts and quality of life*

In Chapter 4 (Section 4.4.5), an attempt was made to reconcile the concepts discussed throughout this thesis with positive psychology theories. A map was produced that denoted outcomes, higher order concepts and lower order concepts (Figure 4.3) and relationships were theorised. However, it proved challenging to integrate quality of life within this map due to its relative neglect within positive psychology theory (Efklides & Moraitou, 2013).

Evidence provided within Chapter 9 indicates that quality of life has measurable implications for positive psychology in older adults with dementia. Specifically, quality of life was a significant predictor of hope, resilience, engagement and independence as measured by the PPOM and EID-Q respectively. It is, therefore, reasonable to suggest that these outcomes are more closely related than previously thought. Within the conceptual map, quality of life may represent a lower order concept (denoted in the conceptual map with green) that influences higher order concepts such as engagement

and positive emotion. This in turn would lead to an increase in flourishing or wellbeing and is supported by the relationship between flourishing and quality of life observed in Chapter 9.

Evidence within this thesis indicates that these two concepts may complement each and, with quality of life currently established as a valuable outcome for dementia research, it is suggested that the relatedness of positive psychology and quality of life is in need of further delineation.

### ***10.2.2 Hope and resilience***

As illustrated in Chapter 3, narratives of dementia tend to reinforce a perception of hopelessness, with dementia portrayed as a tragic loss of a person (Peele, 2014) and hope centred on a cure for people with dementia (Department of Health, 2013).

Furthermore, there has been some suggestion that hope is a cognitive process (Snyder, 2002) and, consequently, it may be lost in people with dementia. In the current research, there was a statistically significant correlation between quality of life and hope contradicting this and providing evidence for the underpinning of hope as a trait like personal strength which underpins wellbeing in dementia (Kitwood & Bredin, 1992).

Within the Values in Action framework (VIA; Peterson & Seligman, 2004), hope was defined as expecting the best in future and working to achieve it. For people with dementia this remained consistent, with hope being described as the expectation of a positive outcome. However, ‘future’ should be open to interpretation as, within Chapters 4 and 5, the future was only discussed within a short time frame, for example, tomorrow or the next day.

*10.2.2.1 States vs Traits debate*

Whether positive psychology concepts such as hope and resilience can be regarded as state or trait has been the subject of much debate. Generally, classification has reflected natural language used when describing these concepts (Allport & Odbert, 1936) and referred to discrete categories. However, others have proposed that the boundaries between these concepts is not always clear cut (Ortony, Clore, & Foss, 1987). To accurately define states and traits, the notion of ‘temporal stability’ is often used, with stability indicating the presence of trait and non-stability indicating the presence of state but this is also subject to debate (Allen & Potkay, 1981). Currently, there is no consensus as to the arbitrary categorization of states and traits, with researchers noting that some concepts have two distinct meanings that would allow dual categorization (Chaplin, John, & Goldberg, 1988).

For positive psychology in particular, research into the delineation of these concepts is currently lacking. However, this has been justified by positive psychology theorists who specify that the focus should be on the concept itself, rather than debates as to whether the concepts are trait-like or state-like: ‘One can investigate either what accounts for moments of happiness or what distinguishes happy from unhappy individuals. Thus, the second thread in these articles is the theme of the positive personality’ (Seligman & Csikszentmihalyi, 2000, p. 8).

Nevertheless, most commonly resilience is referred to as a dynamic and psychosocial process in which people adapt positively using coping strategies. Therefore, it is assumed that resilience is behavior based and can be learned (Allen, Haley, Harris, Fowler, & Pruthi, 2011). However, much of the existing literature base for resilience in dementia is based on a high and low resilience framework (e.g. Windle, 2012), with few

studies identifying the processes by which resilience might be learned in dementia.

Evidence here suggests that, whilst subject to some variability, resilience and other positive psychology concepts remained moderately stable over a one-week period. This may suggest evidence for resilience and other positive concepts to be regarded as state rather than trait, as fluctuation did occur and may have been influenced by external factors.

### ***10.2.3 Independence and Social Engagement***

Independence for people with dementia is widely viewed as a valuable outcome.

However, the definition of independence comes from that of a western and healthy population and may share the same criticism as quality of life. Quality of life as a term is bound by the norms and values of the population it was developed in (Moon, Budts, & De Geest, 2006) and, as such, may not be a true accurate representation of what people with dementia experience. The same is true of independence, which takes its definition from a westernised view of what people are motivated to attain. For people with dementia, independence is often defined as functional independence (Steinberg, Sheppard Keoutsakos, Podewils, & Lyketsos, 2009) and functional ability is taken as an indication of independence. However, when concerned with what contributes to wellbeing, it may be more theoretically appropriate to measure how one feels about one's level of independence rather than the actual ability itself. This would take into account the differing levels of independence that people with dementia reported being desirous of within Chapter 5 here. The EID-Q was designed to measure a subjective assessment of a person with dementia's independence and, therefore, may detect more theoretically appropriate assessments of independence as a contributor to wellbeing than functional assessments.

People with dementia can be at risk of loneliness and social isolation, with a recent survey indicating that 38% of people with dementia reported feeling lonely, compared with 24% of older adults without dementia (Kane & Cook, 2013). Objective measures of social network for older adults exist including the Lubben Social Network Scale (Lubben, 1988). However, these measures do not take into account how individuals feel about the level of contact and the kinds of relationships they have with others. It also does not take into account concepts grouped under a social umbrella that have been well documented, such as the desire of a person with dementia to be in a reciprocal relationship documented within Chapter 5 here and evidenced within the literature. Furthermore, whilst it is well established that severity of dementia has no impact upon a person with dementia's quality of life (Woods 2002), the importance of positive relationships in maintaining wellbeing should not be underestimated (Ryan & Nolan, 2016). It may be that positive relationships in which people with dementia feel they are able to reciprocate and feel connected with those around them tell us more about their wellbeing than objective measures of frequency and duration alone. The EID-Q addresses this, in that it assesses the degree to which people with dementia feel supported.

#### ***10.2.4 Flourishing***

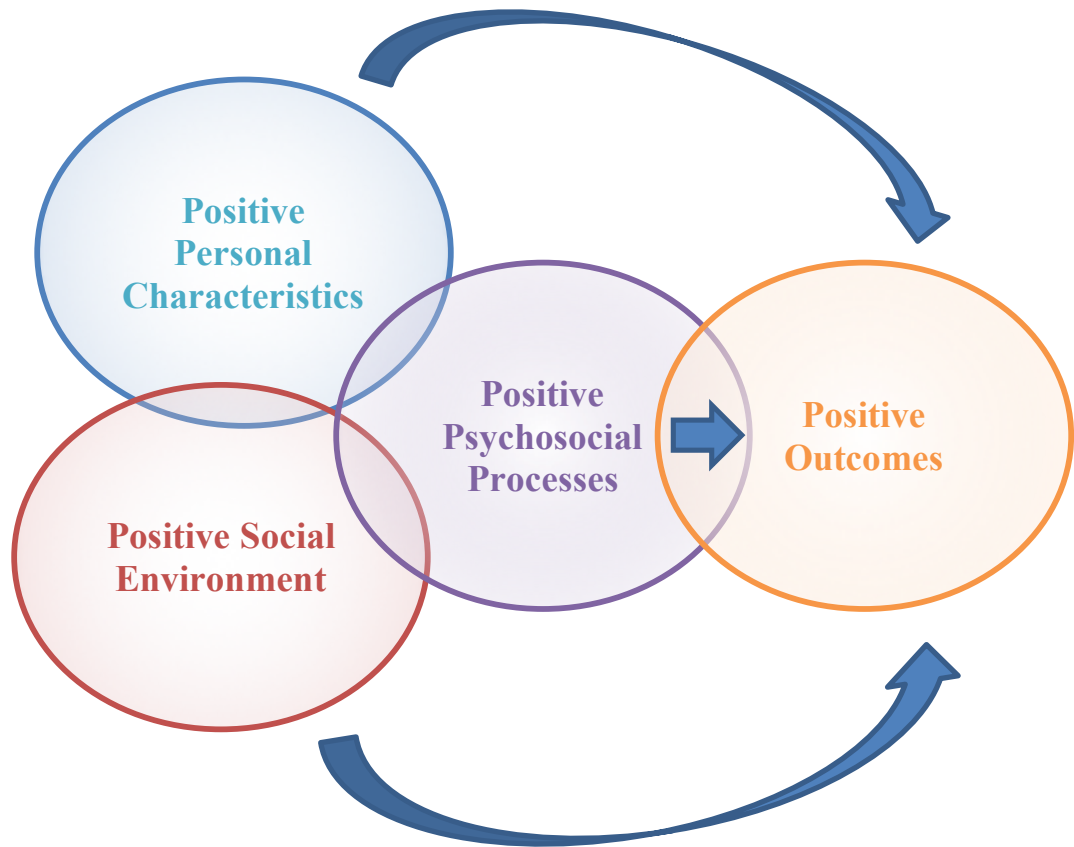
As discussed within Chapter 10, flourishing is defined as a person's ability to live well and achieve an optimal level of functioning characterised by positive relationships, positive emotions, resilience, mastery and growth (Fredrickson & Losada, 2005). Within Chapter 10, evidence emerged for a relationship between the PPOM and EID-Q and this relationship was termed 'flourishing'. This was theorised to be a situation in which a person with dementia had high levels of hope and resilience, were happy with their level of independence and felt supported by others. However, a moderator analysis

in which depression was hypothesised to moderate the PPOM and EID-Q was not supported. This may have been an overly simplistic model of positive psychology and depression in which they were viewed as existing on a continuum. Whilst related, as evidenced by correlational analysis, depressive symptomology and positive psychology concepts may exist in an orthogonal manner. In line with second wave positive psychology (Ivtzan, Lomas, Hefferon, & Worth, 2016), this would mean that both high levels of hope and resilience, for example, may co-exist with high levels of depressive symptomology and vice versa. Therefore, the existence of depression should not mean the absence of positive psychology concepts, much like the absence of depression does not indicate wellbeing. The process by which positive and negative states interact within dementia is lacking in evidence and would benefit from further qualitative work.

#### ***10.2.5 A Potential Model of Dementia and Positive Psychology***

As positive psychology remains very much in its infancy with regard to dementia care and research, frameworks proposed are tentative and untested. An overarching, process-based framework of dementia suggests that there may be an interaction between three components: positive characteristics of the person, positive aspects of the social environment and positive psychosocial processes (Figure 10.1). Positive characteristics refer to character strengths and virtues developed and sustained across the life span. Positive aspects of social environment refer to accepting and mutually supportive relationships and networks where there is also positive wellbeing. Positive psychosocial processes refer to maintaining hopefulness, resilience and experiencing flow through creative activity (Clarke, Wolverson, Stoner, & Spector, 2016).





*Figure 10.1 Tentative framework of Positive Psychology in Dementia*

This systems-based model focuses on that which is observable and measurable, including positive characteristics and strengths making it relevant to the designing of interventions that could enhance specific skills or capabilities for people with dementia. Both the PPOM and EID-Q have relevance to these domains and provide evidence for the model. As a measure of hope and resilience, the PPOM may measure the positive personal characteristics that people with dementia display. The EID-Q assesses the degree to which a person with dementia feels independent and is engaged with those around them and, therefore, may measure the degree to which a person has a positive social environment and engages in positive psychosocial processes. Within Chapter 10, both of these measures were found to be significantly predicted by quality of life and, as such, provide evidence for positive psychology concepts relationship to positive outcomes.

Furthermore, the model provides a contingency in that, if a social environment becomes restricted for a person with dementia, it is still possible to enhance the other domains (positive characteristics) to improve wellbeing.

### **10.3 Methodological Considerations**

#### ***10.3.1 Screening and Demographic information***

Despite having inclusive and clearly defined inclusion criteria, screening against the criteria could be time consuming. Most commonly, participants were aware that they had ‘memory problems’ and were aware they had visited a memory clinic for these memory problems but were unable to recall whether they had been given a diagnosis of dementia. Due to the recruitment avenues (Join Dementia Research (JDR) website, memory clinics, Cognitive Stimulation Therapy (CST) groups and previous research), it made theoretical sense for these participants to have been diagnosed with dementia. Nevertheless, if any participant was unsure as to an actual diagnosis given, this information was obtained from other avenues, for example carers or healthcare records.

Demographic information was, at times, difficult to obtain. Most commonly, participants were unaware of the sub-type of dementia they had been diagnosed with, when they were diagnosed and what medication they were taking. In some cases, a family carer was available to answer these questions, but this was not always possible. If a participant had been recruited via the JDR, information as to subtype was normally available but records could be varied with regard to date of diagnosis and medication. Consent was sought from participants to access this information on the relevant medical records database (e.g. RiO at North East London NHS Foundation Trust) when this information was not otherwise available.

### ***10.3.2 Management of research sites***

Research sites differed in their ability to successfully recruit participants for the psychometric study. When additional sites were first approved, a recruitment target of a minimum of 20 and maximum of 40 participants was set at each site. As North East London NHS Foundation Trust (NELFT) was the primary site, it was expected that the majority of data would be collected here. However, due to limited staffing and the volume of other dementia research that was ongoing at NELFT, recruitment was slower than first hoped. To compensate for this, the maximum threshold for recruitment at sites recruiting more successfully and consistently (Black Country Partnership NHS and Humber NHS) was removed. Whilst this meant that recruitment progressed more efficiently it was, at times, challenging to monitor accruals whilst ensuring that recruitment did not exceed the originally approved sample size. On the first day of each calendar month, staff at each site were responsible for emailing anonymised and up to date participant logs, to ensure that over-recruitment did not occur. This also enabled the swift uploading of accruals on the Clinical Portfolio Management System (CPMS).

### ***10.3.3 Interview and Self-report***

A piece of feedback from a carer pointed out some potential methodological problems, in that a carer assisted a participant to complete the assessments in the guise of a conversation. It was not standard procedure for participants to be interviewed by carers for this study, due to potential bias, and it is not clear how often this occurred. Sites were informed that participants could either complete the study by interview with a trained researcher or by self-report. This participant was categorised as a self-report by the research staff at the site but would probably constitute an interview response in actuality. Sites were not explicitly informed that carers should not assist participants in

completing their answers as it was assumed the people with dementia might require some support (e.g. pointing out missed responses). Future studies may wish to address this by explicitly stating that carers should not infer answers from conversations and that, if participants were unable to answer independently, the research team should be informed so that a trained researcher could attend and assist (Appendix 6.2).

#### ***10.3.4 Management of Risk***

Only one instance of negative feedback was passed on to the primary researcher that outlined an event that had occurred after a participant had completed the study. The day following completion of the study, a participant had driven themselves to a number of areas and was stopped by police officers travelling in the wrong direction on a motorway. The carer inferred that the participant had tried to drive to a number of their previous workplaces and this was related to their involvement within the study. This incident was discussed within the supervisory team and, although unfortunate, it was concluded that it would be impossible to establish a causal relationship between participation in study and the incident. Also, such incidents are hard to foresee and, apart from explaining the nature of the questionnaire and ensuring the participant has capacity to consent, there is very little that can be done to predict and prevent such incidents. In responding to this, a number of steps were taken. Firstly, the RA who received the email responded expressing their sympathy and highlighted that none of the questionnaires mentioned ‘work’, giving examples of items from each questionnaire to evidence this. The RA also passed on the primary researchers contact details in case they wanted to discuss the incident further. Secondly, the primary researcher informed the Joint Research Office (JRO), completed an incident form, and the Risk Assessment Team at University College London (UCL) also assessed the incident. The Risk Assessment Team recommended that all sites were informed of the incident and that the

incident was documented within this thesis. All sites were informed of the incident on the 7<sup>th</sup> November 2016 via email (Appendix 6.3), with a request to cascade the information to all staff working on the study.

## **10.4 Limitations**

### ***10.4.1 Participants with Mild Dementia***

Participants within the current research were required to have capacity to provide informed consent and, consequently, were more likely to be in the milder stages of dementia. Therefore, no conclusions can be drawn about the degree to which people with more advanced dementia use the character strengths outlined here. Whilst there may be issues with articulation towards later stages as language ability declines, there is still a need to properly evidence these concepts to ensure that they are not excluded from positive psychology research. Furthermore, there is a danger that continuing to reside in the community can be used as an indicator of ‘living well’ (Kane & Cook, 2013) and, therefore, of the presence of positive psychology principles, with the assumption being that positive psychology becomes less appropriate for those in later stages of dementia, who may reside in care facilities.

### ***10.4.2 Older Adults with Dementia***

The development of the EID-Q and PPOM (Chapter 5) was conducted with participants who had an average age of 80.56 and the psychometric analysis (Chapter 7) was conducted with participants who had an average age of 77.5. Those under the age of 65 within Chapter 7 consisted of 20 participants and made up 10.9% of the sample. Therefore, the participant pool throughout this thesis predominantly consisted of older adults (65+ years of age) with dementia. It is possible that experiences of positive concepts such as the ones measured by the PPOM and EID-Q differ for people with

early-onset dementia. For example, the absence of future or goal oriented hope discussed within Chapter 5 may not remain valid for younger people with dementia who are often still in employment, have significant financial commitments such as mortgages and have dependent children or parents to care for (Roach, Keady, Bee & Hope, 2008). In addition, people with early-onset dementia report that maintaining independence and meaningful activity is of vital importance for their wellbeing, but this can sometimes be negated by a cessation of employment which, in turn, can cause stress and trauma for the person (Roach & Drummond, 2014). Consequently, the experience of dementia for younger people may be entirely different to older adults and this should be reflected in any measures developed.

To ensure that younger people living with dementia are accurately represented within research, purposeful sampling could be used. Within the recruitment phase for Chapter 7, one specialist Cognitive Stimulation Therapy (CST) group for those under the age of 65 was visited but such groups are rare and only one was conducted during the data collection phase. In addition to this, recruitment avenues in future should include specialist support or counselling groups for people with younger onset dementia as well as seeking input from specialist charities such as Young Dementia UK.

It is, therefore, suggested that the EID-Q and PPOM are adequate instruments to assess positive concepts in older adults with dementia but further qualitative and quantitative work is needed to establish whether they are appropriate for those under the age of 65 living with dementia.

#### ***10.4.3 Representation of Black and Minority Ethnic Groups (BME)***

The main limitation of research documented here was the representation of black and minority ethnic (BME) groups. Whilst the inclusion/ exclusion criteria were purposively encompassing for the psychometric study, BME participants only accounted for 9.8% (n =25/255) of the total sample throughout. This may be because of a lack of diversity at sites to begin with or that the recruitment avenues were not sufficient to ensure representation. As such, the majority of these data reflect positive psychology concepts in White- British people and can make no inferences regarding how BME groups experience positive concepts and the possible cross-cultural implications of this. Future researchers may wish to purposively sample from these groups in order to ensure they are represented within research.

#### ***10.4.4 Assessments of Psychometric Properties***

During the design phase, attention was paid to create a study which required minimal effort for a person with dementia and would enable participants to express a choice as to their manner of completion, whilst being as robust as possible. To accommodate these objectives, outcome measures were selected that were brief in nature and could be completed either by self-report or by interview. This approach had both advantages and limitations. It led to an influx of requests from NHS trusts requesting approval to run the study at their respective sites and allowed a large amount of people with dementia to be recruited and complete the study. However, having brief and limited outcome measures also meant that psychometric analyses, including that of convergent validity, could only focus on the relationship between positive psychology, quality of life and depression.

#### ***10.4.5 Proxy Reporting***

As a wealth of positive psychology research has been conducted with carers of people with dementia, the decision was made to not include carer or proxy outcome measures within the psychometric study (Chapter 7). This decision was made for a number of reasons. Firstly, it enabled people with dementia who could not identify someone to act as a carer to be involved in the study. Secondly, like quality of life, positive concepts are highly subjective in nature and it is likely that discrepancies between self and proxy reports in the quality of life literature may also appear in positive psychology literature (Arons, Krabbe, Schölzel-Dorenbos, van der Wilt, & Olde Rikkert, 2013; Hoe, Hancock, Livingston, & Orrell, 2006). Finally, the aim of this study was to quantitatively document positive concepts that people with dementia have been able to accurately explore within the qualitative literature. To include proxy ratings for subjective concepts, might imply that the person with dementia was unable to accurately make self-judgements and this is not in keeping with the theoretical underpinning of this research. However, this approach meant that no analysis or conclusions could be made as to the relationship between self and proxy ratings of positive concepts for people with dementia.

#### **10.5 Future Research**

Over the course of the psychometric study (Chapter 7), a number of participants and carers provided feedback to research assistants and this was passed on to the primary researcher. Feedback was generally positive, with one participant suggesting that the types of questions participants are generally asked in research studies have an impact upon their wellbeing (Appendix 6.1). It is recommended that this consideration is taken into account when designing future studies for people with dementia.



Chapters 2 and 3 illustrate that there is still a lack of appropriate positive psychology outcome measures for people with dementia and that researchers may not pay enough attention to psychometric considerations as is needed. Future researchers should ensure that the measures they select for people with dementia are appropriate and should consider the degree to which adaption is needed to ensure an adequate level of content validity for people with dementia. Furthermore, a psychometric validation should be conducted and this information should be made available to interested researchers to ensure best practice within research.

As identified within the above limitations section, responsiveness could not be established here. In relation to this, there is currently no consensus as to how positive psychology concepts may be acted upon to improve outcomes for people with dementia. Whilst much research for people with dementia is concerned with reducing behavioural and psychological symptoms of dementia such as agitation or depression (Livingston, et al., 2005), positive psychology research for this population is still lacking. It is suggested that, in addition to research aimed at reducing negative symptoms for people with dementia, research around developing interventions to foster hope, resilience and independence for people with dementia is needed to explore how, if at all, concepts can be acted upon to improve wellbeing.

In order to establish responsiveness of the measures described here, a randomised controlled trial (RCT) is needed. Furthermore, the design of these interventions should be closely aligned with positive psychology principles, ensuring that interventions are theoretically related and intended to produce effects on concepts that are measured by both the PPOM and EID-Q. For the PPOM, it is suggested hope and resilience fostering

interventions may be an appropriate means of assessing responsiveness. The psychosocial benefits, including increased quality of life, of hope fostering interventions in particular, have been noted for older adults receiving palliative care (Duggleby, et al., 2007). The PPOM, therefore, may be an accurate tool to assess the effect of hope fostering interventions for older adults with dementia. For the EID-Q, PRIDE may be an appropriate intervention to establish responsiveness. As discussed throughout this thesis, independence has traditionally been operationalised as a functional ability and social concepts operationalised objectively with the size of one's social network often measured. PRIDE, in contrast, is a social and relational intervention and aims to promote and maintain independence for a person with dementia and their supportive others. It is therefore likely that this intervention may induce improvements in feelings of independence and social world engagement and this improvement may be reflected in improvements on the EID-Q.

On a statistical level, an RCT is often the gold standard for assessing efficacy of interventions (Barton, 2000), and therefore, provides evidence that responsiveness of a measure can be attributed to an intervention rather than random variability within the sample. To assess this, a series of independent samples t-tests and ANCOVA's using baseline differences as covariates would be necessary to provide this evidence. However, it is noted that additional means of establishing responsiveness are available should an RCT not be feasible. One such option, within a lower powered study, would be to assess the percentage change at a participant level between baseline and post-intervention follow ups as has been evidenced in previous studies (e.g. Johnston, et al., 2016). Also, for lower powered studies, the Reliable Change Index (RCI) could be calculated for each measure to ensure that change is greater than the standard error of a measurement (Jacobson & Truax, 1991).

Since this research was conducted, a protocol has been developed for adapting existing measures of positive psychology for people with mild dementia (McGee, Zhao, Myers, & Kim, 2017). Using a process of expert consultation, small-scale piloting and a further analysis using 36 people with mild dementia (maximum Clinical Dementia Rating of 1; Hughes, Berg, Danziger, Coben, & Martin, 1982), the authors assessed measures of gratitude, life satisfaction, meaning in life, optimism and resilience. They concluded that lengthy Likert scales should be condensed and participants should only complete measures by interview, as the four participants within their pilot were unable to complete the measures independently. Whilst this was a good starting point, a sample size of 36 is too low to fully establish adequate psychometric properties of people with dementia and increases the probability of Type II errors. Furthermore, confusion as to the terms used in psychometric evaluations led to convergent validity being referred to as discriminant validity. To ensure that positive psychology measures are grounded in the best possible evidence, future work is needed to develop robust methodologies. The methodology outlined within this thesis can act as an example on which future measure development or validation work can be modelled upon.

## **10.6 Conclusions**

The research documented here is not intended to supplant the prevailing psychology of dementia within research, practice and society with positive psychology principles. Nor is it a tyranny of positives which attempts to deny that people with dementia can face challenges and difficulties. Rather, it is an attempt to challenge the overriding narrative of loss and decline that has dominated research over the past twenty years. It is also an attempt to encourage the viewing of dementia through alternative frameworks so that a more rounded understanding of wellbeing for this population can be evidenced. Using

robust, quantitative methodology, this thesis documents that people with dementia retain and use character strengths and virtues such as hope and resilience in day-to-day life and that these concepts impact upon a person's ability to live well with their diagnosis of dementia.

## 11. References

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## Appendices

### 1. Development Tools

#### *1.1 Summary of informal consultation discussions*

PwD/ Caregiver/ HCP	Setting	Themes Identified	Important constructs identified
<b>Male PwD (G)</b>	Day Centre Attendee	G enjoyed spending time with family and that it was important to be able have help when needed from friends and family. G also said that his family were of vital importance and he enjoyed socialising with children and grandchildren. G also inferred that being confident in oneself was important but felt that he didn't have much. G was unable to articulate what would enable G to feel more confident in everyday life.	1) Connectedness 2) Sociability 3) Confidence
<b>Female PwD (B)</b>	Day Centre Attendee	<p>B talked at length about remaining positive and confident in spite of setbacks in the context of "keeping going". B stressed that it was essential to remain optimistic and to look at the world with humour. B could not stand people who couldn't take a joke and she felt that her sense of humour allowed her to cope with almost anything life threw at her.</p> <p>B commented that she was well travelled and this contributed to a feeling of wisdom. "As you grow you get wiser". Following on from this, B talked about her sociability and that she felt it was important to know that she could rely on her friends and family where appropriate, although she was keen to stress that this was something that she had not done at the time of our discussion.</p> <p>From an observation of B in her morning activity, she seemed to greatly enjoy the company of others and talked with another attendee at length.</p>	1) Resilience 2) Optimism 3) Independence 4) Connectedness / social participation

<b>Female PwD (J)</b>	Day Centre Attendee	<p>J opened our conversation by saying that she felt it was important to feel able to help others within the day centre. She felt this could be by talking and cheering people up or by helping them within activities. J also said that remaining positive and patient were key strengths for her.</p> <p>She stated that it was important for her to feel independent. J stressed that she was aware that others would be there if she needed them but it was important for her to be able to do things for herself e.g. make a sandwich. It was also important for J to be confident in her ability to take care of herself and talk to others.</p> <p>J felt that resilience and hope were interlinked. She stated that in order for one to feel hopeful, one had to remain resilient to life events. She also highlighted Social Engagement/ Participation as a key.</p> <p>She noted that ‘patience’ was missing from the chart and she defined this as ‘doing the little things’ and understanding that she was not able to do things like cook a full dinner anymore but still made the effort to make sandwiches.</p>	<ol style="list-style-type: none"> <li>1) Patience</li> <li>2) Independence</li> <li>3) Self-efficacy</li> <li>4) Social engagement/ participation</li> </ol>
<b>Male PwD (R)</b>	Day Centre Attendee	<p>R felt that his spirituality and religiousness were incredibly important to him. He frequently stated, “What you do in this life, dictates your afterlife”. As such, he felt that God being on his side made life easier for him and that one had to remain hopeful in daily life in order to maintain one’s sense of spirituality.</p> <p>R also stated that remaining independent and having confidence in oneself were largely the same, although he felt that as he aged, his priorities had largely changed and, instead of focusing on himself, he now focused on the wellbeing of his children.</p> <p>All further discussion seemed to centre on his religious beliefs. He stated that hope, self-efficacy and resilience were all interlinked with religion as one “takes decisions in life to achieve everlasting life”. After some prompting by myself, to explore other aspects of positive psychology, R stated social engagement/ participation was also important to him and he enjoyed seeing his children.</p>	<ol style="list-style-type: none"> <li>1) Religiousness/ Spirituality</li> <li>2) Altruism</li> <li>3) Connectedness</li> </ol>



<b>Female PwD (83) (U)</b>	Care home resident	U thought that being able to listen was important and mentioned that she felt it was good to be patient when looking after children and to be always nice. U felt that to be independent you had to “carry on” and “do it yourself”. She also said that you have always got to be confident in yourself.	1) Independence 2) Patience 3) Affability 4) Self-Efficacy
<b>Male PwD (80) (M)</b>	Care home resident	M thought that a having a sense of humour was very important. He also noted that he often feels impatient but would like to be more patient. M had a philosophy of never giving and said that he feels independent but understood he couldn’t go without carers. M felt that resilience could be defined as recovery from “bad things”. He felt that remaining connected to friends and families could be achieved by being affable to others. M defined affable as being open and friendly. He thought that he had confidence in himself and he coped with things by looking ahead. M said that he had problems expressing himself but people being nice and patient helped him feel more confident. M felt that feeling competent should also be on the list and concluded by saying people should be patient with themselves and grateful towards others.	1) Sense of humour 2) Optimism 3) Affability 4) Competence 5) Self-expression self-efficacy
<b>Female PwD (84) (A)</b>	Care home resident	A talked a lot about her family and friends. She felt it was important to see her family and support them if they needed it. A stated that she knew what she was doing and she was happy to do things for herself. She enjoyed helping others and she felt that confidence and independence were quite closely linked, as you had to be “confident in yourself to rely on yourself”. She stated that often you “don’t know where you’re going” but “you have to be patient”. A felt that the hardest part of getting older was worrying and she needed reassurance to make that better.	1) Sociability/ Affability 2) Patience 3) Confidence/ Independence
<b>Female PwD (89) (K)</b>	Care home resident	K thought that most of the concepts on the chart were important generally but she felt it was always important to be optimistic and to “do what needs doing”. She said that she had a nice family and was lucky to be able to talk to people and rely on them if she needed do. K felt it was up to the individual to decide if they wanted to be independent and you had to take life as it comes because “you know what’s coming”. She thought that confidence was like independence in that you have to be confident to be independent.	1) Confidence/ Independence 2) Optimism 3) Affability

<b>Group discussion with three Female PwDs (B1) (84), (B2) (82) &amp; (M) (90)</b>	Care home residents	B1 noted that being happy and cheerful was very important and being optimistic made people feel happy with themselves. B2 added that people should be fair-minded and sharing. B1 felt that patience was very important and people should not “but in to conversations. B2 felt that she lacked confidence and felt that knowledge came with confidence. M noted that being imaginative was important for her and being able to cope with things on one’s own meant that she felt better about herself. B1 said that she often struggled with expressing herself and she needed confidence and patience in order to feel equipped to express herself adequately. M noted it might also be important for B1 to have someone there if she needed help with expressing herself. B2 defined resilience as “not being able to do it today but I will do it tomorrow” and M added that it was accepting you had made a mistake and not being “put off by it” but having the confidence to come back to it later. B1 felt that the hardest part of getting older was not being able to remember things or thinking of the right word in a sentence.	1) Self-expression self-efficacy 2) Optimism 3) Hope 4) Resilience
<b>Male PwD (P) (86)</b>	Care home resident	P immediately singled out independence as important for him. He defined this as knowing what you can and can’t do and relying on others when you need it but doing things that you can do yourself. He said that being confident was tied in with this as without confidence you “can’t do anything” and that you should be confident in what you can and can’t do. P defined resilience as “being able to stand it if there’s trouble” and thought this was important for himself due to his career. He defined his own optimism as wanting “peace in the world” and that one hopes things will be all right in the end but acknowledged that there is nothing he can really do about it. P noted that he enjoyed the company of likeminded people and that being affable was important to him.	1) Independence/ confidence 2) Resilience 3) Optimism 4) Affability
<b>Female PwD (S) (92)</b>	Care home resident	S felt that humour was a great way of coping with things and said that it was important to be confident but also to know when you need help with things. S felt that she couldn’t always get help and this made her anxious. She also mentioned that being connected to people was good and she liked to talk to people but she had “no one” which again made her feel anxious. S stated that the hardest part of getting older would be not getting help and she thought this would be “terrifying”. She felt that she was independent but not by choice as she would like help.	1) Humour 2) Confidence/ independence 3) Sociability
<b>Female PwD (J) (89)</b>	Care home resident	J felt that being hopeful was very important to her and that the hardest part of getting older was accepting it. She said that she struggled with being confident but she felt it was important for others and it was a way of “managing” things. She felt that gratitude was important but was unable to articulate further.	1) Hope 2) Gratitude 3) Self-efficacy

<b>Female Caregiver (K)</b>	Former caregiver to spouse	K identified a number of constructs that she felt were important to her late husband. She noted that an openness to sociability was particularly important and this was vaguely related to connectedness. She felt that the use of humour was important to her late husband and that it was his means of coping with the difficulties he faced as a result of his diagnosis. She felt that being able to remain independent for as long as possible and having the confidence to remain independent in everyday life was vital for her late husband. K noted that spirituality/ religiousness was not at all important for her late husband but stated that for other people this could give a sense of connectedness and, in this way, she felt they were related. She also thought patience would be better defined as self-belief. When discussing K's late husband, K noted that she felt an ability of personal reflection and of discrimination was important, or more specifically, the ability to see what is/ what is not working for an individual. K felt that this was difficult for her husband but thought it may have been an important strength for others with dementia. She stated that measuring resilience may be particularly difficult for this population as memory problems would confound appearance of supposed resilience, when in actuality, the PwD had often forgotten rather than adapted.	K specifically asked to rank top 5 concepts by means of importance: 1) Independence/ Confidence 2) Sociability/ connectedness 3) Humour 4) Gratitude 5) Self-Efficacy  K thought that these personal strengths might lead to an outcome of resilience.
<b>Female HCPs (S) (18) &amp; (A)</b>	Care assistant at care home	A felt that PwD needed to be patient with themselves and give themselves time to articulate what they wanted to say. S felt that being independent was important with regard to self-care and that PwD needed confidence to care for themselves in whichever way they could and as care assistants they would encourage and support this. S felt that most of the residents were sociable in nature and this was something they all enjoyed and it allowed them to feel happy in the home. S felt that the hardest part of getting older for PwD is not being able to do things they were once able to do and A added that fear of losing a support network would be very difficult.	1) Self-expression self-efficacy 2) Patience 3) Self-care self-efficacy 4) Independence

<b>Female HCP (F) (37)</b>	Care assistant at care home	F felt that it was important to be independent for as long as possible and this was linked to an individual's self-worth and their confidence. She felt that remaining connected was particularly important for PwD as, although they may not always remember, they have moments when they do and seeing their families brings a smile. F felt that one could bring humour into a difficult situation and this would build rapport and confidence for PwD. She noted that a lot of the PwD she cared for were quite resilient and optimistic often saying things like "when I get better". She felt that this kept them going. F felt that PwD had confidence in the staff's ability to care for them and that "you're there and they can rely on you if needed". She suggested that the hardest part of ageing may be the gradual decline of independence, giving examples of relying on mobility aids or other people, and seeing other PwD that were more progressed. F felt this was bad for hopefulness. She also felt that being aware of one's deficits could knock a PwD confidence in their ability to do something or express themselves.	1) Independence/ confidence 2) Sociability 3) Humour 4) Resilience/ Hope
<b>Female HCP (T) (44)</b>	Staff training manager at care home	T noted that both optimism and resilience were important for PwD. She felt that resilience could be defined specifically for PwD as coping with their personal world changing. T suggested that remaining connected with friends and family often breaks down when a PwD moves into a care home but she felt it was important to encourage this. She again defined independence specifically for PwD as "how long can I still be me?" and that confidence was often lost with a loss in independence and by building up confidence, one could build up independence. T stated that gratitude should not be on the list, as one should never expect people to be grateful. She felt that working in the care home environment, you had to be used to working without gratitude and that gratitude had some negative connotations with pity. T felt that the hardest part of aging was suddenly becoming an "old person"- a category that has its own distinct rules for how one should behave and be seen. She felt this is something that a lot of PwD could never identify with, as they may have never seen themselves as part of this category. T suggested that this makes people lose their independence as they conform to the norms of the group (self-fulfilling prophecy). She felt this was confounded by people taking away roles and responsibilities from PwD and this led to a decrease in confidence as a result of a loss of independence. T felt that this has implications for conditions like depression.	1) Independence self-efficacy 2) Optimism 3) Resilience

**1.2 The Herth Hope Index (HHI; Herth, 1992)**

<b>Herth Hope Index</b>				
	Strongly disagree	Slightly disagree	Slightly agree	Strongly agree
I have a positive outlook toward life	1	2	3	4
I have goals for the future	1	2	3	4
I feel all alone	1	2	3	4
I can see possibilities in the midst of difficulties	1	2	3	4
I have a faith that gives me comfort	1	2	3	4
I feel scared about my future	1	2	3	4
I can recall happy/joyful times	1	2	3	4
I have deep inner strength	1	2	3	4
I am able to give and receive care/ love	1	2	3	4
I have a sense of direction	1	2	3	4
I believe that each day has potential	1	2	3	4
I feel my life has value and worth	1	2	3	4

### 1.3 Engagement and Independence in Dementia Questionnaire Version 2 (EID-Q V2)

#### **Instructions**

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

<b>EID-Q (V2)</b>					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. There are things I would like to do but I can't	0	1	2	3	4
6. I take part in conversations in ways that I enjoy	0	1	2	3	4
7. I keep myself busy with activities/ hobbies	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I am a burden to others	0	1	2	3	4
10. I have good relationships/ friendships with others	0	1	2	3	4
11. I can make my own decisions as much as I'd like to	0	1	2	3	4
12. I feel I am often ignored by those around me	0	1	2	3	4

13. I feel confident that I can make the right decisions	0	1	2	3	4
14. I feel connected to others	0	1	2	3	4
15. I can do activities that are important to me	0	1	2	3	4
16. I can get in touch with friends/ family if I need to	0	1	2	3	4
17. I feel that people take decisions away from me	0	1	2	3	4
18. My friends/ family care about me	0	1	2	3	4
19. I can arrange my life in a way that suits me best	0	1	2	3	4
20. I can help the people I care about	0	1	2	3	4
21. I feel I am active in everyday life	0	1	2	3	4
22. I can take part in groups/ activities with others	0	1	2	3	4
23. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
24. I feel that my friends/ family want to spend time with me	0	1	2	3	4
25. I can make changes to my life to match my abilities	0	1	2	3	4
26. I can confide in my friends/ family	0	1	2	3	4
27. I can get myself food if I need to	0	1	2	3	4
28. I can help my friends/ family as much as I would like	0	1	2	3	4

**1.4 Positive Psychology Outcome Measure Version 2 (PPOM V2)****Instructions**

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

<b>PPOM (V2)</b>					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
I have a positive outlook on life	0	1	2	3	4
I feel all alone	0	1	2	3	4
I can see positive things in difficult situations	0	1	2	3	4
I have faith in the future	0	1	2	3	4
I feel scared about my future	0	1	2	3	4
I can recall happy/joyful times	0	1	2	3	4
I have inner strength	0	1	2	3	4
I can give and receive care/ love	0	1	2	3	4
I have a sense of direction in life	0	1	2	3	4
I believe that each day has potential	0	1	2	3	4
My life has value and worth	0	1	2	3	4
I am able to adapt to things	0	1	2	3	4
I am able to deal with whatever happens	0	1	2	3	4
I am able to see the humorous side	0	1	2	3	4
I can cope with stress well	0	1	2	3	4
I can bounce back	0	1	2	3	4
I can achieve my goals	0	1	2	3	4
I can stay focused	0	1	2	3	4
I am not easily discouraged	0	1	2	3	4
I am an emotionally strong person	0	1	2	3	4
I can handle unpleasant feelings	0	1	2	3	4



### 1.5 The EID-Q V3

#### **Instructions**

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

<b>EID-Q (V3)</b>					
	<b>Not true at all</b>	<b>Rarely true</b>	<b>Sometimes true</b>	<b>Often true</b>	<b>True nearly all the time</b>
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. I am a burden to others	0	1	2	3	4
6. I enjoy conversations with others	0	1	2	3	4
7. I can make my own decisions as much as I'd like to	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I'm confident in making decisions	0	1	2	3	4
10. I am often ignored by those around me	0	1	2	3	4
11. I can do activities that are important to me	0	1	2	3	4
12. I can get in touch with friends/ family if I need to	0	1	2	3	4

13. People take decisions away from me	0	1	2	3	4
14. My friends/ family care about me	0	1	2	3	4
15. I can arrange my life in a way that suits me best	0	1	2	3	4
16. I can help the people I care about	0	1	2	3	4
17. I feel I am active in everyday life	0	1	2	3	4
18. I can take part in groups/ activities with others	0	1	2	3	4
19. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
20. I feel that my friends/ family want to spend time with me	0	1	2	3	4
21. I can make changes to my life to match my abilities	0	1	2	3	4
22. I can confide in my friends/ family	0	1	2	3	4
23. I can get myself food if I need to	0	1	2	3	4
24. I can help my friends/ family as much as I would like	0	1	2	3	4
25. I keep myself busy with activities/ hobbies	0	1	2	3	4
26. I feel connected to others	0	1	2	3	4

**1.6 The PPOM V3**

Version 3

07/06/16

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

<b>PPOM V3</b>					
	<b>Not true at all</b>	<b>Rarely true</b>	<b>Sometimes true</b>	<b>Often true</b>	<b>True nearly all the time</b>
I have a positive outlook on life	0	1	2	3	4
I can see positive things in difficult situations	0	1	2	3	4
I can recall happy/ joyful times	0	1	2	3	4
I have inner strength	0	1	2	3	4
I can give and receive care/ love	0	1	2	3	4
I have a sense of direction in life	0	1	2	3	4
I believe that each day has potential	0	1	2	3	4
My life has value and worth	0	1	2	3	4
I am able to adapt to things	0	1	2	3	4
I am able to deal with whatever happens	0	1	2	3	4
I am able to see the humorous side	0	1	2	3	4
I can cope with stress well	0	1	2	3	4
I can bounce back	0	1	2	3	4
I can stay focused	0	1	2	3	4
I am an emotionally strong person	0	1	2	3	4
I can handle unpleasant feelings	0	1	2	3	4

**1.7 EID-Q Five Subscale Solution**

<b>EID-Q</b>						
		<b>Not true at all</b>	<b>Rarely true</b>	<b>Sometimes true</b>	<b>Often true</b>	<b>True nearly all the time</b>
<i>Activities of daily living</i>	I can arrange my life in a way that suits me best	0	1	2	3	4
	I feel I am active in everyday life	0	1	2	3	4
	I can adapt my wishes to be in line with what I can do	0	1	2	3	4
	I can make changes to my life to match my abilities	0	1	2	3	4
	I can get myself food if I need to	0	1	2	3	4
	I am a burden to others	0	1	2	3	4
<i>Decision making</i>	I can look after myself as much as I need to	0	1	2	3	4
	I can make my own decisions as much as I'd like to	0	1	2	3	4
	I'm confident in making decisions	0	1	2	3	4
	People take decisions away from me	0	1	2	3	4
<i>Activity Engagement</i>	I have hobbies/ activities that I enjoy doing	0	1	2	3	4
	I can do activities that are important to me	0	1	2	3	4
	I keep myself busy with activities/ hobbies	0	1	2	3	4
<i>Support</i>	I have people who I can talk to if I need to	0	1	2	3	4
	I enjoy conversations with others	0	1	2	3	4
	There are people I could ask for help if I need to	0	1	2	3	4

	I can get in touch with friends/ family if I need to	0	1	2	3	4
	My friends/ family care about me	0	1	2	3	4
	I feel that my friends/ family want to spend time with me	0	1	2	3	4
	I can confide in my friends/ family	0	1	2	3	4
<i>Reciprocity</i>	I have a role in my social circle	0	1	2	3	4
	I am often ignored by those around me	0	1	2	3	4
	I can help the people I care about	0	1	2	3	4
	I can take part in groups/ activities with others	0	1	2	3	4
	I can help my friends/ family as much as I would like	0	1	2	3	4
	I feel connected to others	0	1	2	3	4

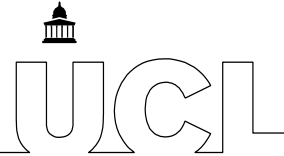
## 2. Information Sheets and Consent Forms

### 2.1 Positive Psychology Outcome Measures for People (PPOM) with Dementia

#### Summary Information Sheet

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RESEARCH DEPARTMENT OF CLINICAL,  
EDUCATIONAL AND HEALTH PSYCHOLOGY  
UNIVERSITY COLLEGE LONDON  
1-19 TORRINGTON PLACE  
LONDON  
WC1E 6BT



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#### INVITATION TO TAKE PART IN A RESEARCH STUDY: POSITIVE PSYCHOLOGY OUTCOME MEASURES (PPOM)

Dear Sir/ Madam,

This is an invitation to take part in a research study. You do not have to take part in this study and even if you chose to take part, you can stop at any point without giving any reason.

The study is being done as part of a PhD project, in which new questionnaires that aim to assess personal strengths including hope and resilience have been developed.

This study involves answering questions on a questionnaire. You will be asked to complete the two new questionnaires and three other questionnaires also. This will take about 30 minutes. We would like to see you again the following week to repeat these questionnaires.

You can complete the study in your own time at your convenience. You may wish to be posted the questionnaires, emailed them or have a researcher bring them to a place of your choice and help you fill them in. This is your choice and we will talk all the options through, if you want to participate.

The researcher will arrange to telephone you at a time that is convenient for you to explain the study in further detail and answer any questions you have.

If you do agree to take part, the researcher will ask you to sign a consent form and ask you some initial questions over the telephone.

Thank you for considering this piece of research.

Yours faithfully,  
Charlotte.

*Additional information V3*

12/12/2016

## 2.2 PPOM Participant Information Sheet

RESEARCH DEPARTMENT OF CLINICAL,  
EDUCATIONAL AND HEALTH PSYCHOLOGY  
UNIVERSITY COLLEGE LONDON  
1-19 TORRINGTON PLACE  
LONDON  
WC1E 6BT



### PARTICIPANT INFORMATION SHEET

#### POSITIVE PSYCHOLOGY OUTCOME MEASURES (PPOM)

##### **Invitation to participate in a research study**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can ask us if there is anything that is not clear or if you would like more information. Thank you for reading this information sheet.

##### **Why have I been invited?**

We are inviting you to take part in this study because you have attended a Memory Clinic, or another NHS service that is providing their patients with the opportunity to take part in research or have registered your interest for taking part in research via the 'Join Dementia Research' (JDR).

##### **What is the purpose of the study?**

This study is part of a PhD project and is aiming to increase understanding of which personal strengths contribute to wellbeing. We have developed two new questionnaires that aim to assess levels of independence, hope, resilience and sociability for people with memory problems. We will collect this information, alongside questions about wellbeing, to better understand how personal strengths may improve quality of life for people.

##### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision to not take part, will not affect any other care you might be receiving.

##### **What does taking part involve?**

If you agree to take part, a researcher will contact you to discuss how you would like to complete the questionnaires. You may wish to complete them in an online format, for which you will be sent a link, or you may wish to arrange with the researcher to visit you at home (or another place that is convenient for you) at a time that suits you. This is your choice, and the researcher will discuss these options with you. During the initial contact, the researcher

*Information sheet for participants- Version 3*  
*Contact: Charlotte Stoner*

*PPOM 12/12/2016*  
*Email: charlotte.stoner.14@ucl.ac.uk*

will discuss the study with you, check that you are ready to take part and then ask you some initial questions. Following this, we will ask you to complete the questionnaires, either online or with a researcher depending on your preference. This should take approximately 30 minutes but if you start to feel tired before, you can continue another day.

We would like to see you again in approximately one week, to repeat these questionnaires so that we can see how you are and if anything has changed for you in that time. Completing the questionnaires for a second time can be done at a time and place that is convenient for you.

**What are the possible disadvantages of taking part?**

We do not consider taking part will involve any disadvantages or specific risks or that it would cause you any harm.

**What are the possible benefits of taking part?**

We hope that you will find the study interesting and enjoy talking to the researcher to complete the questionnaires. If you do decide to take part in this project, you will be making a very valuable contribution in helping us improve understanding of personal strengths and wellbeing.

**What if something goes wrong?**

If you are unhappy or dissatisfied with any aspect of your participation, we would ask you firstly to speak to the researcher, so that we can try to address your concerns and find a solution. You can talk to the researcher or to Dr Aimee Spector (see contact details below).

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital's duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

Participants can also contact the Patient Liaison Services (PALS) at University College London Hospital to discuss their concerns (see contact details below).

**Will my taking part in this study be kept confidential?**

All information collected about you during the course of the study will be kept strictly confidential. Any personal details are kept separate from the information recorded about you during the course of the study to ensure that no-one outside of the research team will be able to identify you personally from these records. The only situation in which we might need to share information about you with other professionals would be if the researchers observe or hear anything that causes very serious concern about your health, safety or wellbeing. This could include possible risk to yourself, risk to others, criminal behaviour or professional misconduct. If this happens the researchers have a duty of care to inform an appropriate professional, such as your GP or primary clinician. We would make every effort to explain to you why we need to share this information before doing so.

We will also ask your permission for us to store, in anonymised form, the information that we collect from you for long-term use, in data archives provided by University College London. This would mean that information could be shared with accredited researchers in future so



that they might understand more and learn from the information we collect also. No one would ever be able to identify you personally from the archived information.

**Who is organising the research?**

The study is being organised by Charlotte Stoner; a PhD student at University College London (UCL) and is funded by UCL's Grand Challenges Studentship.

**Who has reviewed this study?**

All NHS research is reviewed by independent groups of people, called a research ethics committee, to protect patient safety, rights, wellbeing and dignity.

**What will happen to the results of this study?**

The results of this study will be presented at conferences, published in scientific journals and information will be provided for healthcare professionals. Participants will be kept informed of about the progress of the project and results, if they express a desire to receive further information.

**Who can I contact for further information?**

For more information about this research, please contact:

**If you have any concerns or complaints about anything to do with this study, please contact:**

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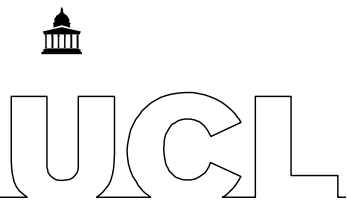
**Thank you for taking the time to consider taking part in this research study.**

*Information sheet for participants- Version 3*  
*Contact: Charlotte Stoner*

*PPOM 12/12/2016*  
*Email: charlotte.stoner.14@ucl.ac.uk*

2.3 PPOM Consent Form

RESEARCH DEPARTMENT OF CLINICAL,  
EDUCATIONAL AND HEALTH PSYCHOLOGY  
UNIVERSITY COLLEGE LONDON  
1-19 TORRINGTON PLACE  
LONDON  
WC1E 7HB



**PARTICIPANT CONSENT FORM**  
**POSITIVE PSYCHOLOGY OUTCOME MEASURES (PPOM)**

Please Initial

1. I confirm that I have read and understood the ‘Positive Psychology Outcome Measures’ Participant Information Sheet (Version 3, 12/12/2016) for the above study.
2. I have had the opportunity to ask questions and have had these answered to my satisfaction.
3. I understand that my participation is completely voluntary and that I am free to withdraw at any time, without giving a reason. I understand that withdrawing will not affect my healthcare or legal rights.
4. I understand that if I choose to withdraw from the study, anonymous data collected to date may be retained.
5. I understand that if any disclosures of possible harm to myself/ others or professional misconduct are made to the research team, the research team has a legal responsibility to inform the relevant professionals.
6. I agree to take part in the study.

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Name of Participant	Date	Signature
-----	-----	-----
Name of Researcher	Date	Signature

Consent form for participants- Version 3

PPOM 12/12/2016

Once completed: one copy for researcher and one for participant.

## 2.6 MBCT Participant Information Sheet



RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY



### PARTICIPANT INFORMATION SHEET

**Study Title:** A Mindfulness-Based Cognitive Therapy (MBCT) Group for People with Memory Problems and Low Mood (Student Research Project)

#### Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Thank you for reading this information sheet.

#### What is the purpose of the study?

This study aims to find out whether mindfulness training can help improve the mood, anxiety and quality of life of people experiencing memory problems and low mood.

#### Who is organising and funding the research?

The research is being organised by University College London and funded by the Oxford Mindfulness Centre. The study will be conducted by Deirdre Noone and Jacob Payne. They work as Trainee Clinical Psychologists, and the study will form part of an educational qualification for both researchers (Doctorate in Clinical Psychology) at University College London (UCL). They are being supervised by Dr. Aimee Spector and Dr. Josh Stott, who are both Clinical Psychologists based at UCL.

#### What is mindfulness training?

Mindfulness is a way of training our attention to focus on the present moment, and to be kinder towards ourselves. Much of the time our minds are lost in thoughts about the past or the future. Living more in the 'here and now' may change our relationship with stress and worry.

Research has shown mindfulness training to be helpful for many different kinds of people experiencing a range of difficulties, and there has been some limited research that suggests mindfulness may be beneficial for people with memory problems. Therefore, this study is designed to find out if people with memory problems attending mindfulness training experience improvements in their: mood, anxiety, quality of life and thinking.

We want to see if mindfulness training is better than usual care that people receive in services such as memory clinics and Improving Access to Psychological Therapies (IAPT) services. To do this, we will use a randomized controlled trial design, whereby half of the people that take part in the study will attend mindfulness sessions and half will receive usual care. The fairest way to decide whether or not people have the opportunity to attend the mindfulness sessions is by chance. The allocation will be done using an independent computer that will not contain any personal information about you.

If you attend the mindfulness sessions you will be invited to attend an interview after the group. This will give you the opportunity to discuss your experience of attending the group.

This study is a 'pilot'. This means it is a small-scale study that will be used to prepare for a larger study. This pilot will help test out and improve the way future studies in this area are conducted.

### **What happens in mindfulness training?**

Mindfulness training is a free eight-week course, and sessions take place once a week, lasting for about 60 minutes each time. The sessions will involve a group of about 5-10 people with low mood and memory problems. During the sessions you will do activities like: gentle breathing and learning to focus on your body.

### **Why have I been invited to take part?**

You have been invited to take part because you are considered to be experiencing difficulties with your memory and mood.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

If you decide to take part, you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

### **What will happen to me if I take part?**

Following discussion of any questions you may have with a researcher, and signing the consent form, all participants will be asked to:

- Meet with a researcher for around one hour to answer questions about your attention, mood, anxiety, quality of life and thinking. The time stated to complete the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary, and if you prefer we can meet for more sessions to finish these.
- Either attend eight-weekly mindfulness training sessions OR receive your usual care for eight weeks.
- Meet with a researcher again to answer the same questions as before. In order to complete the assessment, the researcher may ask to meet a family member or your clinician to complete some questionnaires. The mindfulness training sessions will be audio recorded and will be kept password protected.
- If you attend the eight-weekly mindfulness training sessions, you will be invited to attend an interview to discuss your experience of attending the group.

### **What do I have to do?**

You can carry on your everyday activities as normal while participating in the study. All we ask is that if you are allocated to the mindfulness group, you try to attend all 8 sessions. We understand there may be times when you are unwell and therefore unable to attend a session.

### **What are the possible disadvantages and risks of taking part?**

We appreciate that when you are experiencing memory problems, it may be hard to talk about things like your mood and quality of life. The researcher carrying out the assessments and interviews is someone who has clinical experience and is working under supervision.

You will be encouraged but never forced to take part in a particular activity during the sessions. Overall the risks of taking part in this study are minimal. However, if being involved in this research really does not suit you, for example if you find it distressing, you are free to withdraw at any point.

## 2.7 MBCT Consent Form



### Participant Consent Form

**Study Title:** A Mindfulness-Based Cognitive Therapy (MBCT) Group for People with Memory Problems and Low Mood in Memory Clinic: A Feasibility Pilot Study (Student Research Project).

**Participant Number:**

**Name of Researchers:** Deirdre Noone and Jacob Payne

**Chief Investigator:** Dr. Aimee Spector

**Academic Supervisors:** Dr. Aimee Spector and Dr. Josh Stott

Please Initial Boxes

I confirm that I have read and understand the information sheet dated [insert date, insert version] for the above study, have had the opportunity to ask questions and have had these answered acceptably.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that sections of any of my medical notes and data collected during the study may be looked at by individuals involved in the study, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records	
I give permission for the MBCT sessions to be recorded for supervision purposes	

I give permission for my GP to be informed of my participation in the study	
I understand that all information given by me or about me will be treated as confidential by the research team.	
I agree to take part in the above study	

Name of participant	Date	Signature
Name of person taking consent (if different from the principal researcher)	Date	Signature
Principal researcher	Date	Signature

### 3. Ethics Letter and Insurance

#### 3.1 East of England (Essex) Research Ethics Committee Approval Letter



## Health Research Authority

### East of England - Essex Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0207 104 8069

08 February 2016

Dr Aimee Spector

Study title:	Evaluation of positive psychology outcome measures for use within psychosocial dementia research.
REC reference:	15/EE/0443
IRAS project ID:	186196

Thank you for your response to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Ms Helen Poole at [NRESCcommittee.EastofEngland-Essex@nhs.net](mailto:NRESCcommittee.EastofEngland-Essex@nhs.net)

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).



## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance]	1	
Interview schedules or topic guides for participants [Additional info for online completion]	1	10 September 2015
Letter from sponsor [Sponsor Letter- Insurance]	1	12 October 2015
Letters of invitation to participant [Lay information sheet]	1	04 January 2016
Non-validated questionnaire [Sense of Independence V1]	1	30 August 2015
Non-validated questionnaire [Positive Psychology Outcome Measure (PPOM)]	2	04 January 2016
Non-validated questionnaire [Engagement and Independence in Dementia Questionnaire (EID-Q)]	2	04 January 2016
Other [Clarification re. Additional Changes to PIS (Insurance changes)]		03 February 2016
Participant consent form [Consent form]	2	04 January 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	04 January 2016
REC Application Form [REC_Form_20012016]		20 January 2016
Referee's report or other scientific critique report [Peer Review of Protocol]	1	08 October 2015
Referee's report or other scientific critique report [Sponsorship review]	1	05 October 2015
Referee's report or other scientific critique report [GCP certificate ]	1	19 November 2015
Research protocol or project proposal [Research Protocol]	2	04 January 2016
Summary CV for Chief Investigator (CI) [CI Summary CV]	1	04 February 2015
Summary CV for student [Summary CV]	1	09 September 2015
Validated questionnaire [CASP-19]	1	11 September 2015
Validated questionnaire [Quality of Life in AD]	1	11 September 2015
Validated questionnaire [Geriatric Depression Scale]	1	10 September 2015

## Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## After ethical review

### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators

- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### **HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>15/EE/0443</b>	<b>Please quote this number on all correspondence</b>
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With the Committee's best wishes for the success of this project.

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Email: [NRESCommittee.EastofEngland-Essex@nhs.net](mailto:NRESCommittee.EastofEngland-Essex@nhs.net)

*Enclosures:* "After ethical review – guidance for researchers"

*Copy to:* Ms Smaragda Agathou  
Ms Fiona Horton, North East London NHS Foundation Trust

### 3.2 Health Research Authority Approval



Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

30 June 2016

Dear Dr Spector,

**Letter of HRA Approval for  
a study with an existing  
UK study wide review**

**Study title:** Evaluation of positive psychology outcome measures for  
use within psychosocial dementia research.  
**IRAS project ID:** 186196  
**Sponsor:** University College London

Thank you for your request to bring the above referenced study under HRA Approval.

I am pleased to confirm that the study has been given **HRA Approval**. This has been issued on the basis that a study wide review has previously been undertaken, which has confirmed that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to add a new site between 23 March 2016 and the date of this letter, the addition of the new site is also approved.

**Participation of NHS Organisations in England**

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with HRA Approval Processes. It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate Statement of Activities and HRA Schedule of Events. The sponsor should also provide the template agreement to

be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study.

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### After HRA Approval

In addition to the document, *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

IRAS project ID	186196
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**HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the [HRA website](#).

Your IRAS project ID is **186196**. Please quote this on all correspondence.

Yours sincerely

David Williams  
Application Administrator

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

*Copy to: Ms Smaragda Agathou*

*Ms Fiona Horton*  
*North East London Foundation Trust*

### 3.3 North East London NHS Foundation Trust (NELFT) Research and Development Approval



Research and Development Office  
North East London NHS Foundation Trust,  
1<sup>st</sup> Floor Maggie Lilley Suite,  
Goodmayes Hospital,  
Barley Lane,  
Goodmayes,  
Essex, IG3 8XJ

Date: 11/04/16

Dear Dr Aimee Spector,

**Re: Positive psychology outcome measures for people with dementia**

**NIHR Portfolio ID: 20201**

**IRAS project ID: 186196**

**REC Ref: 15/EE/0443**

I am pleased to inform you that the above named study has been granted approval and indemnity by North East London NHS Foundation Trust. You must act in accordance with the North East London NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1 form.

The documents reviewed and approved for use here at North East London NHS Foundation Trust are as follows:

Document	Version	Date
Protocol	2	04 January 2016
REC approval letter		08 February 2016
Evidence of UCL Sponsor insurance		
Additional info for online completion	1	10 September 2015
Sponsor Letter – Insurance	1	12 October 2015
Lay information sheet	1	04 January 2016
Non-validated questionnaire – Sense of Independence	1	30 August 2015
Non-validated questionnaire – Positive Psychology Outcome Measure (PPOM)	2	04 January 2016
Non-validated questionnaire – Engagement and Independence in Dementia Questionnaire (EID-Q)	2	04 January 2016
Participant consent form	2	04 January 2016
Participant information sheet	2	04 January 2016

Peer review of protocol	1	08 October 2015
Sponsorship review	1	05 October 2015
Charlotte Stoner GCP certificate		19 November 2015
Validated questionnaire – CASP-19	1	11 September 2015
R&D application	186196/90 9345/14/3 44	25 January 2016
SSI application	186196/92 9893/6/81 3/297709/ 342276	13 January 2016
Validated questionnaire – Quality of Life in AD	1	11 September 2015
Validated questionnaire – Geriatric Depression Scale	1	11 September 2015
Chief Investigator CV – Dr Aimee Spector		
Researcher CV – Charlotte Stoner		

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

Research and Development Manager,  
North East London NHS Foundation Trust

## 3.4 HRA Statement of Activities for participating NHS Trusts



# HRA Statement of Activities Health Research Authority

## for Participating NHS Organisations in England (template version 4.1)

*For non-commercial studies, one Statement of Activities should be completed as a template for each site-type in the study. Each Statement of Activities should be accompanied by a completed HRA Schedule of Events, as part of the submission via IRAS for HRA Approval.*

**Blue shaded fields (also marked with an asterisk\*) should be completed by the sponsor/applicant prior to submission to the HRA.**

Where appropriate, for the purpose of confirming capacity and capability, green shaded fields (also marked with a caret^\*) should be completed by the participating organisation before returning the document to the sponsor.

Other questions may be completed either by the sponsor/applicant or participating organisation (or collaboratively between both parties), as appropriate.

*For participating organisations in Northern Ireland, Scotland or Wales, the sponsor should transfer a Site Specific Information Form to each local research team for completion and submission to their research management support function.*

*To provide an answer in the form, click in a box with the blue text and over-write this text, or select the relevant option if presented with drop-down text. A separate guidance document is provided and should be consulted prior to completion of this template. Please also read the question specific guidance where present.*

<b>IRAS ID*</b>	186196
<b>Short Study Title*</b>	Positive psychology outcome measures for people with dementia
<b>Full Study Title*</b>	Evaluation of positive psychology outcome measures for use within psychosocial dementia research
<b>Contact details of sponsor, or sponsor's delegated point of contact (e.g. Study Manager), for questions relating to study set-up*</b>	Charlotte Stoner
<b>Site Type*</b>	Recruiting Site <b>Select one option. If 'Other', give details.</b> If 'Other', insert details here

<b>Name of Participating Organisation</b>	<i>Where this statement is to be used as the agreement between sponsor and participating organisation, the name of the participating organisation should be entered here prior to agreement. If this Statement is being agreed to cover multiple separate entities (e.g. multiple GP practices within a single LCRN geography) please make this clear here.</i>
<b>Location/s within Participating Organisation</b>	<i>Where the research is planned to take place only at specified hospitals or other locations within the participating organisation (as may be the case in an NHS Trust comprised of more than one hospital) please name those hospitals/locations here.</i>

<b>Date</b>	<b>Date template assessed by HRA</b>
-------------	--------------------------------------

HRA Statement of Activities, template version 4.1, 10 May 2016

1

186196



<b>HRA Office Use Only</b>	
<b>Version Number</b>	Applicant version assessed by HRA
<b>HRA Office Use Only</b>	

**1. Does the sponsor intend that this document forms the agreement between itself and the participating organisation/s in England?\***

*For non-commercial studies other than clinical trials and clinical investigations, the HRA encourages use of the Statement of Activities as the only form of agreement between sponsor and an English participating organisation, in place of bespoke agreements created by sponsors. For research in primary care settings, the Statement may be used for a geographical area, e.g. at the LCRN level, although agreement should be between the sponsor and independent legal entity (e.g. GP Practice). For clinical trials and clinical investigations the HRA expects that sponsors will use the relevant model agreement, where one exists.*

Yes

**2. Date this Statement of Activities confirmed by participating organisation, if applicable.^**

Enter date confirmed

**3. Confirmation on behalf of participating organisation provided by (insert name and job title), if applicable.^**

Enter name and job title

*It is not intended that this confirmation requires wet-ink signatures, or a passing of hard copies between the sponsor and participating organisation. Instead, sponsors are expected to accept confirmation by email from an individual empowered by the participating organisation to agree to the commencement of research (including any budgetary responsibility, where the study involves the transfer of funds).*

**4. If this Statement is not intended to form the agreement with the participating organisation/s in England, will the sponsor be using an unmodified model non-commercial agreement?\***

Select 'yes' or 'no'

**5. If no, please provide details of the modifications made to the model agreement and the reasons for them. If the sponsor intends to use an agreement not based on the model agreement, please provide detailed justification for this (templates of all 'site agreements' to be used, including for sites in the devolved administrations (where applicable) should be provided as part of the submission for HRA Approval).\***

Provide details of modification made to model agreement and the reasons for them

**6. Predicted Participant Recruitment, if applicable.**

*This is recruitment or identification at participating organisation, not overall for the study. Please clarify if this refers to participants, samples or data. Please clearly state if this is per month, per year, overall etc. Leave blank if not applicable to this site type.*

Minimum of 20 participants, maximum of 40 participants between July 2016 and July 2017.

**7. Proposed start date of research/participant identification activity at participating organisation.**

*Where it might otherwise be open to interpretation, please specify whether this date refers to the commencement of screening, the recruitment of the first participant, etc.*

01/07/2016

Commencement of identification, consent and completion of study for participants

**8. Predicted end date of research/participant identification activity at participating organisation.**

*Where it might otherwise be open to interpretation, please specify whether this date refers to the recruitment of the final participant, the final visit of the final participant, database lock, etc.*

Date that final participant has completed study

completion of study

**9. Person responsible for research activities at site.\***

Local Principal Investigator

*The HRA expects Principal investigators to be in place at participating organisations where locally employed staff take responsibility for research procedures. Where this is not the case, the HRA expects Local Collaborators to be in place where central study staff will be present at site to undertake research procedures (the role of the Local Collaborator is to support practical arrangements for the presence of research staff under Letters of Access or Honorary Research Contracts). Where existing data is being provided for research purposes without additional research procedures and without the presence of central research team members at site, the HRA does not expect that a Principal Investigator or Local Collaborator is appointed and you should select Chief Investigator.*

**10. Are you requesting support to identify a Principal Investigator or Local Collaborator?\***

*Please indicate whether support from the host organisation is being requested to identify a Principal Investigator/Local Collaborator and provide further information on expectations below. Where a Principal Investigator or Local Collaborator has already been identified, their details appear on Part C of the IRAS Form.*

No

**11. Further Information (where applicable).\***

*Please provide further information on sponsor expectations for a Principal Investigator/Local Collaborator, to help participating organisations identify an appropriate individual if required (e.g. Profession, specialty, seniority etc.)*

Provide information on the support required

**12. The following capabilities and capacity are needed locally in order to deliver the study, e.g. specific equipment, patient/participant groups, service support nursing time, excess treatment costs, etc.\***

*Any funding or support from the sponsor/funder to the participating organisation is set out in the Finance Schedule.*

Capability and capacity to identify, take informed consent and complete study with a minimum of 20 participants per site

**13. Projected NHS Treatment Cost savings at this site type, if applicable.\***

*Although many studies incur Excess Treatment Costs (see [AcoRD](#) for information on cost attribution) many studies also give rise to treatment cost savings during the study (e.g. a two armed study comparing standard care to a less intensive, and less expensive, alternative treatment). Please describe below any projected treatment cost savings, so your participating organisations may include this information when considering the overall treatment costs/cost savings of their portfolio of research. Any funding or support from the sponsor/funder to the participating organisation is set out in the Finance Schedule. Excess Treatment Costs will be indicated above (question 12) and in the HRA Schedule of Events.*

Provide information on projected treatment cost savings (or leave blank if not applicable)

**14. The following training for local staff will be provided by the sponsor. Where only specific team members (e.g. the Principal Investigator) will receive this training, this is described below.\***

Protocol & measures to be delivered to research delivery team. To be provided at the site initiation telephone call.

**15. In addition to the above training, to be provided by the sponsor, the sponsor also expects that the following local research team members will undertake or have already undertaken the following training.\***

*It would not be usual for the sponsor to expect study specific training additional to that which it will provide, this section does however allow sponsors to state that they will accept, for example, NIHR CRN training in Good Clinical Practice where the study is a Clinical Trial of an Investigational Medicinal Product etc.*

Informed consent training, GCP training

## Schedule 3 (Confidentiality, Data Protection and Freedom of Information) (template version 4.1)

Please select one of the following*	
<b><i>This study does not involve the transfer of Personal Data from this participating organisation to the sponsor or its agents, nor is there transfer of confidential information between the parties. This schedule does not form part of this agreement.*</i></b>	<input type="checkbox"/>
<b><i>The Sponsor has separately provided to the HRA and participating organisation another agreement for the transfer of data. This schedule does not form part of this agreement.*</i></b>	<input type="checkbox"/>
<b><i>These provisions form part of the agreement between the sponsor and this participating organisation. Select this option if no other agreement is provided, and the terms below constitute the arrangements for this study.*<sup>4</sup></i></b>	<input checked="" type="checkbox"/>

### 1. Participant Confidentiality

- 1.1. The parties agree to adhere to all applicable statutory requirements and mandatory codes of practice in respect of confidentiality (including medical confidentiality) in relation to participants
- 1.2. Personal Data shall not be disclosed to the sponsor by the participating organisation, save where this is required directly or indirectly to satisfy the requirements of the Protocol, or for the purpose of monitoring or reporting adverse events, or in relation to a claim or proceeding brought by a participant in connection with the study.
- 1.3. Neither the sponsor nor the participating organisation shall disclose the identity of participants to third parties without the prior written consent of the participant except in accordance with applicable statutory requirements and codes of practice, including HSCIC Code of Practice on Confidential Information.
- 1.4. The sponsor agrees to act as Data Controller in relation to any processing of Personal Data under this agreement. This extends to all processing that would not have taken place but for this agreement regardless where that processing takes place. In particular, it extends to processing by the participating organisation where that processing is undertaken solely for the purposes of the study.
- 1.5. The sponsor agrees to comply with the obligations placed on a Data Controller by the Data Protection Act 1998. This is not limited to, but includes, ensuring that:
  - 1.5.1. Personal Data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes
  - 1.5.2. Personal Data are adequate, relevant and not excessive in relation to the purpose or purposes described within the protocol.
  - 1.5.3. Personal Data shall be accurate and, where necessary, kept up to date.
  - 1.5.4. Personal Data shall be processed in accordance with the rights of data subjects under the Data Protection Act 1998.
- 1.6. The Sponsor agrees to ensure appropriate training. In particular:
  - 1.6.1. To ensure that any persons (excluding employees, honorary employees, students, researchers, consultants and subcontractors of the Participating Site) processing

<sup>4</sup> The HRA Statement of Activities is not intended for use with participating organisations in Northern Ireland, Scotland or Wales.

- Personal Data are subject to annual mandatory training in the information governance responsibilities and have appropriate contracts including sanctions, including for breach of confidence or misuse of data;
- 1.6.2. To ensure that the Senior Information Risk Owners, e.g. Caldicott Guardians, senior partners and board members of the sponsor (or organisational equivalent of each of these) complete additional data security training annually.
  - 1.7. The participating organisation agrees to ensure that its employees, honorary employees, students, researchers, consultants and subcontractors processing Personal Data are subject to annual mandatory training in the information governance responsibilities and have appropriate contracts including sanctions, including for breach of confidence or misuse of data;
  - 1.8. The sponsor agrees to use Personal Data solely in connection with the operation of this agreement and the study and not otherwise. In particular;
    - 1.8.1. Not to disclose Personal Data in whole or in part to any person without the participating organisation's prior written consent;
    - 1.8.2. Not to disclose other than pursuant to a data sharing agreement that conforms to the requirements set out in the Information Commissioner's data sharing code of practice.
  - 1.9. The participating organisation agrees to act as Data Processor on behalf of the sponsor as Data Controller for processing undertaken under this agreement solely for the purposes of the study. The participating organisation agrees to comply with the obligations placed on it as the data controller by the seventh data protection principle ("the Seventh Principle") set out in the Data Protection Act 1998, namely:
    - 1.9.3. to maintain technical and organisational security measures sufficient to comply at least with the obligations imposed on the Data Controller by the Seventh Principle;
    - 1.9.4. only to process Personal Data for and on behalf of the Data Controller, in accordance with the instructions of the Data Controller and for the purpose of the study and to ensure the Data Controller's compliance with the Data Protection Act 1998;
    - 1.9.5. to allow the sponsor to audit the participating organisation's compliance with the requirements of this clause on reasonable notice and/or to provide the Data Controller with evidence of its compliance with the obligations set out in this clause;
    - 1.9.6. the participating organisation shall obtain prior agreement of the sponsor to store or process Personal Data at sites outside the European Economic Area (comprising the countries of the European Community, Norway, Iceland and Liechtenstein).
  2. Freedom of Information
    - 2.1. Parties to this agreement which are subject to the Environmental Information Regulations 2004 (EIR) and the Freedom of Information Act 2000 (FOIA) or the Freedom of Information (Scotland) Act 2002 (FOI(S)A) and which receive a request under EIR, FOIA or FOI(S)A to disclose any information that belongs to another party shall notify and consult that party, as soon as reasonably practicable, and in any event, not later than seven (7) calendar days after receiving the request.
    - 2.2. The parties acknowledge and agree that the decision on whether any exemption applies to a request for disclosure of recorded information under EIR, FOIA or FOI(S)A is a decision solely for the party responding to the request.
    - 2.3. Where the party responding to an EIR, FOIA or FOI(S)A request determines that it will disclose information it will notify the other party in writing, giving at least four (4) calendar days' notice of its intended disclosure.
  3. Confidential information

- 3.1. The receiving party agrees to take all reasonable steps to protect the confidentiality of the confidential information and to prevent it from being disclosed otherwise than in accordance with this agreement.
- 3.2. Subject to clause 3.4 below, the participating organisation agrees to treat the results, excluding any clinical data of the study, as confidential information disclosed by the sponsor and the sponsor agrees to treat Personal Data as confidential information disclosed by the participating organisation.
- 3.3. The receiving party agrees:
  - 3.3.1. To ensure that any of its employees, students, researchers, consultants or sub-contractors who participate in the operation of the study are made aware of, and abide by, the requirement of this clause 3 and, where relevant, clause 2.
  - 3.3.2. To use confidential information solely in connection with the operation of the agreement and not otherwise.
  - 3.3.3. Not to disclose confidential information in whole or in part to any person without the disclosing party's prior written consent.
- 3.4. The provision of clause 3 shall not apply to the whole or any part of the confidential information that is:
  - 3.4.1. lawfully obtained by the receiving party free of any duty of confidentiality;
  - 3.4.2. already in the possession of the receiving party and which the receiving party can show from written records was already in its possession (other than as a result of a breach of clause 3.1 or 3.2);
  - 3.4.3. in the public domain (other than as a result of a breach of clause 3.1 or 3.2);
  - 3.4.4. independently discovered by employees of the receiving party without access to or use of confidential information;
  - 3.4.5. necessarily disclosed by the receiving party pursuant to a statutory obligation;
  - 3.4.6. disclosed with prior written consent of the disclosing party;
  - 3.4.7. necessarily disclosed by the receiving party by virtue of its status as a public authority in terms of the Freedom of Information Act 2000;
  - 3.4.8. published in accordance with HRA expectations on research transparency.
- 3.5. The restrictions contained in clauses 2 and 3 shall remain in force without limit in time in respect of Personal Data or which relates to a patient, his or her treatment and/or medical records. Save as aforesaid and unless otherwise expressly set out in this Agreement, these clauses shall remain in force for a period of 10 years after the termination or expiry of this Agreement.

### 3.5 Confirmation of Insurance (UCL)



#### UCL/UCLH Joint Research Office

**Office Location:**  
1<sup>st</sup> Floor Maple House  
149 Tottenham Court Road  
London W1T 7DN

**Postal Address:**  
UCL,  
Gower Street  
London WC1E 6BT

12/10/2015

Dear Charlotte,

**Chief Investigator:** Dr Aimee Spector

**Study/Trial Title:** Positive psychology outcome measures for people with dementia

**Funder:** UCL / Promoting Independence in Dementia

**UCL Project ID No.** 15/0721

**Re: Insurance for studies not involving a Clinical Trial of an Investigational Medicinal Product (non-CTIMP) sponsored by UCL**

Thank you for completing the UCL Insurance Registration Form dated 08/10/2015. I am pleased to inform you that the above study, as described in the registration form, is now insured under UCL's policy. A copy of the current insurance summary (Verification of Insurance) is attached to this letter.

The policy provides for the legal liabilities (negligence) of UCL and its' employees or agents.

This confirmation letter, together with the attached summary, needs to be submitted to the Research Ethics Committee in support of question A76 for both your NHS REC and, where applicable, NHS R&D applications submitted via the Integrated Research Application System (IRAS).

/Continued

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Director Research Support Centre, Director R&D UCLH – Brian Williams  
Managing Director Research Support Centre – Dr Nick McNally

UCL Insurance Confirmation Letter  
Version 13: 30.07.2015



Page 2 / Continued

The UCL insurance policy is renewed annually, but studies included in the UCL insurance portfolio will be automatically rolled over into subsequent insurance period(s) until the study terminates. Indemnity and insurance arrangements for any participating sites will be detailed in individual Site Agreements.

Please keep a copy of this letter for your records. Feel free to contact me if you have any queries concerning the insurance cover.

Yours sincerely,

  
Database & Information Officer

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Director Research Support Centre, Director R&D UCLH – Brian Williams  
Managing Director Research Support Centre – Dr Nick McNally

UCL Insurance Confirmation Letter  
Version 13: 30.07.2015



### 3.6 Substantial Amendment 1



## Health Research Authority

### East of England - Essex Research Ethics Committee

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

14 June 2016

Dear Dr Spector

<b>Study title:</b>	<b>Evaluation of positive psychology outcome measures for use within psychosocial dementia research.</b>
<b>REC reference:</b>	<b>15/EE/0443</b>
<b>Amendment number:</b>	<b>01</b>
<b>Amendment date:</b>	<b>08 June 2016</b>
<b>IRAS project ID:</b>	<b>186196</b>

The above amendment was reviewed 14 June 2016 by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The sub-committee agreed the amendment presented no ethical issues.

#### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Non-validated questionnaire [EID-Q (tracked changes)]	2	
Non-validated questionnaire [EID-Q ]	3	
Non-validated questionnaire [PROM (tracked changes)]	2	
Non-validated questionnaire [PROM]	3	
Notice of Substantial Amendment (non-CTIMP)	01	08 June 2016
Other [Covering Email]		08 June 2016

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.



**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>15/EE/0443:</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

E-mail: [NRESCommittee.EastofEngland-Essex@nhs.net](mailto:NRESCommittee.EastofEngland-Essex@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Fiona Horton, North East London Foundation Trust  
Ms Smaragda Agathou*



## Health Research Authority

East of England - Essex Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 13 June 2016

**Committee Members:**

<i>Profession</i>	<i>Present</i>
Consultant Oncologist	Yes
Pharmacist	Yes

**Also in attendance:**

<i>Position (or reason for attending)</i>
REC Assistant

### ***3.7 Substantial Amendment 2***

Dear Charlotte Stoner

-  
**Please quote these on all  
correspondence**

<b>IRAS Project ID:</b>	<b>186196</b>
<b>Amendment No./ Sponsor Ref:</b>	<b>2</b>
<b>Amendment Date:</b>	<b>19 December 2016</b>

Further to the below, I am pleased to confirm that HRA Approval has been issued for the referenced amendment, following assessment against the HRA criteria and standards.

The sponsor should now work collaboratively with participating NHS organisations in England to implement the amendment as per the below categorisation information. This email may be provided by the sponsor to participating organisations in England to evidence that the amendment has HRA Approval.

Please contact [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net) for any queries relating to the assessment of this amendment.

Yours sincerely,

Dear Charlotte Stoner

<b>IRAS Project ID:</b>	<b>186196</b>
<b>REC Reference:</b>	<b>15/EE/0443</b>
<b>Short Study Title:</b>	<b>Positive psychology outcome measures for people with dementia</b>
<b>Date complete amendment submission received:</b>	<b>19 December 2016</b>
<b>Amendment No./ Sponsor Ref:</b>	<b>2</b>
<b>Amendment Date:</b>	<b>19 December 2016</b>
<b>Amendment Type:</b>	<b>Substantial</b>

Thank you for submitting the above referenced amendment. I am pleased to confirm that this amendment has been submitted to the REC for ethical review. Please find attached a copy of the

validation letter.

### **Categorisation of Amendment**

In line with the UK Process for Handling UK Study Amendments I can confirm that this amendment has been categorised as:

- **Category A** - An amendment that has implications for, or affects, ALL participating NHS organisations  
You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the three conditions below, you will be able to implement the amendment at your participating NHS organisations in England **35 days after you notify them of the amendment**. A template email to notify participating NHS organisations in England is provided [here](#).

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion, (for participating organisations in England, this includes receiving confirmation of HRA Approval for the amendment). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England, plus to local research teams at any participating NHS organisations in Northern Ireland, Scotland or Wales\*.
- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.

- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.

**Note:** you may only implement changes described in the amendment notice or letter.

If you receive required regulatory approvals (for participating organisations in England, this includes confirmation that the amendment has been granted HRA Approval) after the 35 days have passed, you may then immediately implement this amendment at all participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study.

There is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35 day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.

\* Where the study involves NHS organisations in Northern Ireland, Scotland or Wales, the HRA will forward regulatory approvals to the relevant national coordinating function to distribute to their research management support offices.

Please do not hesitate to contact me if you require further information.

Kind regards

## 4. Instruments

### 4.1 PPOM Pilot Data Collection Measure Booklet



<b>Participant Identifier</b> - - - - -
--



## Positive Psychology Outcome Measures for People with Dementia- PILOT (PPOM)

### Participant Identifier key:

- All ID's should start with 'P'
- Following this, should be either 'R' (care home) or 'C' (community) depending on where the participant lives.
- Finally participants should be given a number in ascending order.

e.g. PR001, PC002, PC003 etc





Participant Identifier

- - - - -



Date of Birth: \_\_\_\_\_

Male/ Female: \_\_\_\_\_

**Marital status:**

- ☐ Single  
☐ Married  
☐ Widowed  
☐ Divorced  
☐ Other (please specify):  
 \_\_\_\_\_

**Ethnicity:**

- ☐ White (British)  
☐ White (Other)  
☐ Asian  
☐ Black  
☐ Mixed  
☐ Other (please specify)  
 \_\_\_\_\_

**Dementia diagnosis:**

- ☐ Alzheimer's Disease  
☐ Vascular dementia  
☐ Mixed dementia (Alzheimer's and Vascular)  
☐ Parkinson's related dementia  
☐ Picks Disease  
☐ Other (please specify)  
 \_\_\_\_\_

**Please list any major mental/ physical health problems that you currently experience:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Date of diagnosis of dementia (if known). If you do not know the exact date, please provide an estimate:**

\_\_\_\_\_

**What medication are you currently taking?**

\_\_\_\_\_

\_\_\_\_\_



Participant Identifier

- - - - -



We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

PPOM (V2)					
	Not true at all	Rarely true	Sometime s true	Often true	True nearly all the time
I have a positive outlook on life	0	1	2	3	4
I feel all alone	0	1	2	3	4
I can see positive things in difficult situations	0	1	2	3	4
I have faith in the future	0	1	2	3	4
I feel scared about my future	0	1	2	3	4
I can recall happy/ joyful times	0	1	2	3	4
I have inner strength	0	1	2	3	4
I can give and receive care/ love	0	1	2	3	4
I have a sense of direction in life	0	1	2	3	4
I believe that each day has potential	0	1	2	3	4
My life has value and worth	0	1	2	3	4
I am able to adapt to things	0	1	2	3	4
I am able to deal with whatever happens	0	1	2	3	4
I am able to see the humorous side	0	1	2	3	4
I can cope with stress well	0	1	2	3	4
I can bounce back	0	1	2	3	4
I can achieve my goals	0	1	2	3	4
I can stay focused	0	1	2	3	4
I am not easily discouraged	0	1	2	3	4
I am an emotionally strong person	0	1	2	3	4
I can handle unpleasant feelings	0	1	2	3	4

<b>CASP-19</b>				
	Often	Sometimes	Not often	Never
My age prevents me from doing the things I would like to	0	1	2	3
I feel that what happens to me is out of my control	0	1	2	3
I feel free to plan for the future	0	1	2	3
I feel left out of things	0	1	2	3
I can do the things that I want to do	0	1	2	3
Family responsibilities prevent me from doing what I want to do	0	1	2	3
I feel that I can please myself with what I can do	0	1	2	3
My health stops me doing the things I want to do	0	1	2	3
Shortage of money stops me from doing the things that I want to do	0	1	2	3
I look forward to each day	0	1	2	3
I feel that my life has meaning	0	1	2	3
I enjoy the things that I can do	0	1	2	3
I enjoy being in the company of others	0	1	2	3
On balance, I look back on my life with a sense of happiness	0	1	2	3
I feel full of energy these days	0	1	2	3
I choose to do things that I have never done before	0	1	2	3
I feel satisfied with the way my life has turned out	0	1	2	3
I feel that life is full of opportunities	0	1	2	3
I feel the future looks good for me	0	1	2	3



Participant Identifier

- - - - -



We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

<b>EID-Q (V2)</b>					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. There are things I would like to do but I can't	0	1	2	3	4
6. I take part in conversations in ways that I enjoy	0	1	2	3	4
7. I keep myself busy with activities/ hobbies	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I am a burden to others	0	1	2	3	4
10. I have good relationships/ friendships with others	0	1	2	3	4
11. I can make my own decisions as much as I'd like to	0	1	2	3	4
12. I feel I am often ignored by those around me	0	1	2	3	4



Participant Identifier

- - - - -



	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
13. I feel confident that I can make the right decisions	0	1	2	3	4
14. I feel connected to others	0	1	2	3	4
15. I can do activities that are important to me	0	1	2	3	4
16. I can get in touch with friends/ family if I need to	0	1	2	3	4
17. I feel that people take decisions away from me	0	1	2	3	4
18. My friends/ family care about me	0	1	2	3	4
19. I can arrange my life in a way that suits me best	0	1	2	3	4
20. I can help the people I care about	0	1	2	3	4
21. I feel I am active in everyday life	0	1	2	3	4
22. I can take part in groups/ activities with others	0	1	2	3	4
23. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
24. I feel that my friends/ family want to spend time with me	0	1	2	3	4
25. I can make changes to my life to match my abilities	0	1	2	3	4
26. I can confide in my friends/ family	0	1	2	3	4
27. I can get myself food if I need to	0	1	2	3	4
28. I can help my friends/ family as much as I would like	0	1	2	3	4



Participant Identifier

- - - - -



GDS	
Question	Answer (please circle)
Are you basically satisfied with your life?	Yes/ No
Have you dropped many of your activities or interests	Yes/ No
Do you feel that your life is empty?	Yes/ No
Do you often get bored?	Yes/ No
Are you in good spirits most of the time?	Yes/ No
Are you afraid that something bad is going to happen to you?	Yes/ No
Do you feel happy most of the time?	Yes/ No
Do you feel helpless?	Yes/ No
Do you prefer to stay at home/ in your room, rather than go out and do things?	Yes/ No
Do you feel that you have more problems with your memory than most?	Yes/ No
Do you think it is wonderful to be alive now?	Yes/ No
Do you feel pretty worthless the way you are now?	Yes/ No
Do you feel full of energy?	Yes/ No
Do you feel that your situation is hopeless?	Yes/ No
Do you think that most people are better off than you are?	Yes/ No
<b>TOTAL</b>	



Participant Identifier

- - - - -



Please circle either **poor**, **fair**, **good** or **excellent** for each of the questions. Please circle only one answer. If you are unsure, circle your best guess.

QoL-AD				
Currently, how would you rate your:				
Physical health?	Poor	Fair	Good	Excellent
Energy?	Poor	Fair	Good	Excellent
Mood?	Poor	Fair	Good	Excellent
Living situation?	Poor	Fair	Good	Excellent
Memory?	Poor	Fair	Good	Excellent
Family?	Poor	Fair	Good	Excellent
Marriage/ closest relationship?	Poor	Fair	Good	Excellent
Friends?	Poor	Fair	Good	Excellent
Self as a whole?	Poor	Fair	Good	Excellent
Ability to do chores around the house?	Poor	Fair	Good	Excellent
Ability to do things for fun?	Poor	Fair	Good	Excellent
Money/ financial situation?	Poor	Fair	Good	Excellent
Life as a whole?	Poor	Fair	Good	Excellent

## 5. Presentations and Publications

### 5.1 List of Publications and Presentations

**Stoner, C.R.**, Orrell, M., Long, M., Csipke, E. & Spector, A. (2017). The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: The PPOM and the EID-Q. *BMC Geriatrics*, 17(72), 1-11.

Stansfeld J., **Stoner, C.R.**, Wenborn, J., Vernooij-Dassen, M., Moniz-Cook, E. & Orrell, M. (2017) Positive psychology outcome measures for family caregivers of people living with dementia: A systematic review. *International Psychogeriatrics*, May24, 1-16.

**Stoner, C.R.**, Stansfeld, J., Orrell, M. & Spector, A. (2017). The development of positive psychology outcome measures and their uses in dementia research: A systematic review. *Journal of Positive Psychology*, under review.

McDermott, O., Charlesworth, G., Hogervost, E., **Stoner, C.**, Moniz-Cook, E., Spector, A., Csipke, E. & Orrell, M. (2017). Psychosocial interventions for people with dementia: A synthesis of systematic reviews. *Aging & Mental Health*, under review.

Feast, A., Moniz-Cook, E., **Stoner C.**, Charlesworth, G. & Orrell, M. (2016). A systematic review of the relationship between behavioral and psychological symptoms (BPSD) and caregiver well-being. *International Psychogeriatrics*, Jun27, 1-14.

Clarke, C., Wolverson, E. **Stoner, C.** & Spector, A. (2016) Overview and Ways Forward for a Positive Psychology Approach to Dementia. In Positive C. Clarke & E. Wolverson (Eds.) *Psychology Approaches to Dementia*. London: Jessica Kingsley.



World Federation of Occupational Therapists., Streater, A., **Stoner, C.**, Curchod, L. & Ledgerd, R. (2016). World Federation of Occupational Therapists human resources project 2016: Demographic profile of WFOT member organisations. *World Federation of Occupational Therapists Bulletin*, DOI: 10.1080/14473828.2016.1275407

Stansfeld, J., **Stoner, C.R.**, Wenborn, J., Vernooij-Dassen, M., & Orrell, M. (2016). *Systematic review of positive psychology measures for family carers of people living with dementia*. Poster presented at Alzheimer's Disease Congress, London, UK.

Spector, A., Hebditch, M., **Stoner, C. R.**, & Gibbor, L. (2016). A biopsychosocial vignette for case conceptualisation in dementia (VIG-Dem). *International Psychogeriatrics*, Apr7, 1-10.

**Stoner, C. R.**, Orrell, M., & Spector, A. (2016). *Moving beyond quality of life: Positive psychology and dementia*. Poster presented at the Alzheimer's Disease International Conference, Budapest, Hungary.

**Stoner, C. R.**, Long, M., Orrell, M., Csipke, E., & Spector A. (2016). *Sense of independence: meanings and implications as told by people with dementia*. Poster presented at Alzheimer's Disease International Conference, Budapest, Hungary.

**Stoner, C. R.**, Orrell, M., & Spector, A. (2015). Review of positive psychology outcome measures for chronic illness, traumatic brain injury and older adults: Adaptability in dementia. *Dementia and Geriatric Cognitive Disorders*, 40(5-6), 340-357

## 5.2 Moving Beyond Quality of Life: Positive Psychology and Dementia Poster

(Poster presented at Alzheimer's Disease International (ADI) in Budapest, 2016).

# Moving Beyond Quality of Life: Positive Psychology and Dementia

Charlotte R. Stoner<sup>1</sup>, Martin Orrell<sup>2</sup> and Aimee Spector<sup>1</sup>

<sup>1</sup>Clinical, Educational and Health Psychology, UCL. <sup>2</sup>Institute of Mental Health, University of Nottingham

### Positive Psychology Towards an 'asset-based' approach

Term coined by Abraham Maslow but re-introduced by Martin Seligman (1998). Emphasises the importance of documenting what actions lead to well-being in an **empirically sound manner**.

### Positive Psychology and Dementia Examples from the qualitative literature

"I help my wife to get dressed  
....It is natural because we  
have always helped each other  
and we both enjoy it"

Engaging with life

"Still enjoy walking and reading  
in particular...and I still  
enjoy listening to music"

Seeking pleasure/enjoyment

"...I'm in complete control of my  
own, whatever I want, intend  
to do"

Agency

"I've got into the habit of making  
a joke about it otherwise it  
would take over my life"

Humour

### Review of positive psychology outcome measures for chronic illness, traumatic brain injury and older adults: Adaptability in dementia? (Stoner, Orrell & Spector 2015)

**Aim** – To assess the psychometric properties of positive psychology outcome measures in use for chronic illness, TBI and older adult populations. Also, to appraise the potential applicability of these measures for people with dementia

**Inclusion** – Studies published between 1998- 2015 that reported the development or psychometric testing of an outcome measure for a specific construct, as identified in the search terms, within positive psychology for chronic illness, TBI and older adult populations.

**Exclusion** – Papers published in a language other than English if a translation was not available. Also, papers that focused on external or situational factors rather than an internal trait within positive psychology.

**Results** – 16 positive psychology outcome measures and 8 further psychometric assessments of these were identified. Outcome measure development procedures were assessed for quality with the 'Terwee Criteria'. Most were of moderate methodological quality, of which the CASP-19 scored highest.

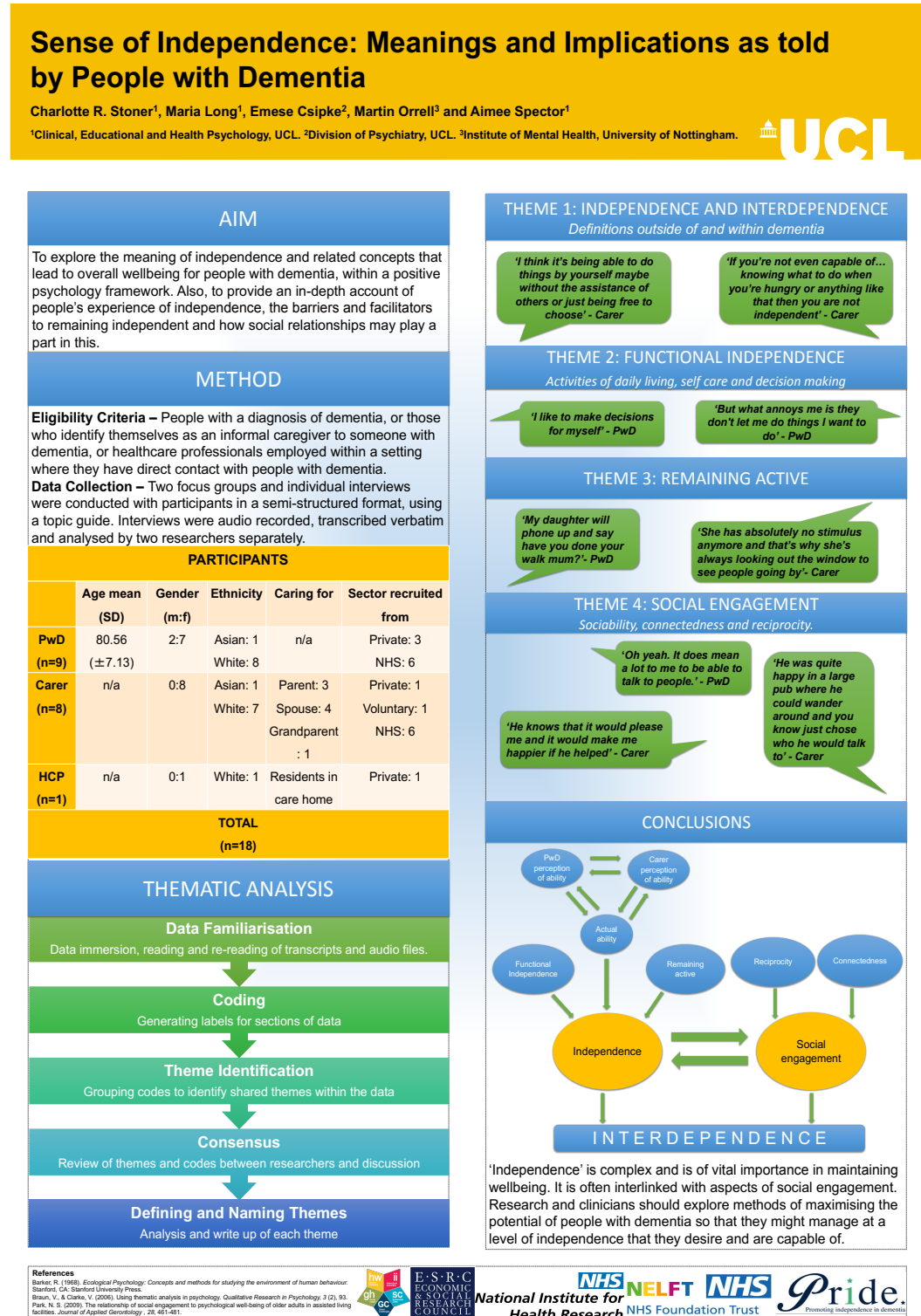
Construct	Outcome measure	Population developed for	Quality score /18
Self efficacy	Care-Receiver Self Efficacy Scale	American functionally disabled older adults	7
	Connor-Davidson Resilience Scale	American sample	7
Resilience	Brief Resilient Coping Scale	American Sample with Rheumatoid Arthritis	2
	The Resilience Scale	American women	7
	The Brief Resilience Scale	American undergraduates and chronic illness sample	6
	Daily Spiritual Experience Scale	American chronic illness sample	6
Spirituality	Spirituality index of wellbeing	Community dwelling older adults	4
	Geriatric Spiritual Wellbeing Scale	American community dwelling older	7
Life Valuation	FACT - Spiritual Wellbeing Scale	American cancer patients	7
	The Satisfaction with Life Scale	American undergraduate students	3
	Valuation of Life Scale	American older adults	5
	Attitude toward Aging Scale	Portuguese community dwelling older adults	6
Autonomy	Maastricht Personal Autonomy Questionnaire	Older adults with chronic physical	8
Sense of Coherence	Sense of Coherence Scale	Jewish population	2
Resourcefulness	The Resourcefulness Scale for Older Adults	Older adults	5
Other	Control, Autonomy, Self-realisation and Pleasure	British older adults	9

**Key conclusions** – The qualitative literature documents the retained capacity of people with dementia to use character strengths and provides a rationale for the use of positive psychology concepts and an asset based approach to dementia care and research. Outcome measures identified within the above review have potential utility for psychosocial research and are in need of psychometric validation for people with dementia.

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 Stoner, C. R., Orrell, M., & Spector, A. (2015). Review of positive psychology outcome measures for chronic illness, traumatic brain injury and older adults: Adaptability in dementia. *Dementia and Geriatric Cognitive Disorders*, 40(5-6), 340-357.  
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 Wolverson, E. L., Clarke, C., & Moritz-Cook, E. D. (2015). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Aging & Mental Health*, 1-24.  
 Wolverson, E. L., Clarke, C., & Moritz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health*, 14 (6), 450-460.

### 5.3 Sense of Independence: Meanings and Implications as told by People with Dementia Poster

(Poster presented at ADI conference in Budapest, 2016)



## 5.4 The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: The PPOM and the EID-Q

Stoner et al. *BMC Geriatrics* (2017) 17:72  
DOI 10.1186/s12877-017-0468-6

BMC Geriatrics

### RESEARCH ARTICLE

### Open Access



# The development and preliminary psychometric properties of two positive psychology outcome measures for people with dementia: the PPOM and the EID-Q

Charlotte R. Stoner<sup>1\*</sup>, Martin Orrell<sup>2</sup>, Maria Long<sup>3</sup>, Emese Cspike<sup>4</sup> and Aimee Spector<sup>1</sup>

## Abstract

**Background:** Positive psychology research in dementia care has largely been confined to the qualitative literature because of the lack of robust outcome measures. The aim of this study was to develop positive psychology outcome measures for people with dementia.

**Methods:** Two measures were each developed in four stages. Firstly, literature reviews were conducted to identify and operationalise salient positive psychology themes in the qualitative literature and to examine existing measures of positive psychology. Secondly, themes were discussed within a qualitative study to add content validity for identified concepts ( $n = 17$ ). Thirdly, draft measures were submitted to a panel of experts for feedback ( $n = 6$ ). Finally, measures were used in a small-scale pilot study ( $n = 33$ ) to establish psychometric properties.

**Results:** Salient positive psychology themes were identified as hope, resilience, a sense of independence and social engagement. Existing measures of hope and resilience were adapted to form the Positive Psychology Outcome Measure (PPOM). Due to the inter-relatedness of independence and engagement for people with dementia, 28 items were developed for a new scale of Engagement and Independence in Dementia Questionnaire (EID-Q) following extensive qualitative work. Both measures demonstrated acceptable internal consistency ( $\alpha = .849$  and  $\alpha = .907$  respectively) and convergent validity.

**Conclusions:** Two new positive psychology outcome measures were developed using a robust four-stage procedure. Preliminary psychometric data was adequate and the measures were easy to use, and acceptable for people with dementia.

**Keywords:** Dementia, Positive psychology, Independence, Hope, Resilience, Outcome measure, Psychometric

## Background

Outcome measures utilised within dementia research have generally been constructed using a loss/deficit approach, in which measures have been designed to examine co-morbid conditions such as anxiety [1] and depression [2] or behavioural and psychological symptoms of dementia (BPSD) [3]. Quality of life is often used as a primary outcome within research but this is not without issue. Often the overriding aim of such research is to

reduce BPSD and it is inferred that this reduction should theoretically lead to an increase in quality of life [4]. However, this perspective has limitations as it does not include the perspective of the person with dementia.

Positive psychology may contribute to the concept of wellbeing for this population. Positive psychology refers to the study of positive emotions that enable individuals, communities and organisations to thrive [5], and advocates the use of quantitative methods to examine such positive concepts. Examples of positive concepts include humour, resilience, growth and spirituality. However, currently this approach is in its infancy and a lack of gold standard outcome measures means that positive attributes, experiences

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and outcomes are under researched for people with dementia [6] and the reporting of positive experiences of people with dementia is limited to the qualitative literature.

To examine the positive psychology concepts and their relationship to wellbeing, valid and reliable outcome measures are needed. The aim of this study was to develop such measures to be used in further research and clinical practice. It is hoped this will lead to a more asset based approach to the study of dementia and enable people to further live well with their diagnosis.

## Method

In order to develop these measures, we undertook a four stage process. Stage one consisted of a literature review in which evidence of positive psychology concepts from the qualitative dementia literature was sourced and examined. The most salient themes from these searches was developed into a topic guide for stage two. Stage two consisted of a qualitative study, in which positive psychology themes were explored with people with dementia and their carers to generate items for measures. Stage three consisted of expert feedback in which xdraft items within measures were examined for clarity, difficulty and content validity. Finally these measures were piloted with a small scale sample of people with dementia. These processes are discussed in more detail below.

### Stage 1: literature review

Qualitative literature published between 1998 and 2015 that investigated positive psychology concepts for people with dementia was examined. Search terms were: goal, self-efficacy, hope, resilience, coping, wisdom, growth, sense of coherence, control, autonomy, pleasure, self-realisation, sense of agency, gratitude, happiness, optimism, transcendence, positive, dignity, social participation, social inclusion, self-concept, humour, creativity, flow, spirituality, love, compassion, benefit finding, community integration, opportunity, social adjustment, mindfulness, acceptance, successful aging AND dementia, lewy body, vascular, Alzheimer, cognitive impairment, old, elder. Truncations of search terms were used where appropriate. For the purpose of this section, the Seligman definition of positive psychology [7] was used to screen results. This search enabled the authors to identify salient concepts in order to produce a topic guide for the focus group stage of development. Concurrently, searches were conducted to identify existing, robust outcome measures that could be adapted for people with dementia. Search terms above were used again but search terms denoting dementia were changed for the search terms: measure, instrument, questionnaire, quiz, test.

### Stage 2: focus groups

#### Design

A cross-sectional sectional qualitative design was used in which participants explored the meaning and implications of independence, social engagement, hope and resilience in dementia. Qualitative studies are recommended when designing outcome measures to ensure an adequate level of content validity [8]. A topic guide and semi-structured interview format were used to facilitate discussion and elicit in-depth views on subjective experience of this construct.

#### Participants

Ethical approval was obtained and participants were recruited through one private organisation (a care home in Leeds) and an existing Cognitive Stimulation Therapy (CST) group within a London NHS trust between September and October 2015. The CST group was identified as an appropriate source of recruitment for the focus group, as it was an established group consisting of people with mild dementia. People with dementia and carers were interviewed separately either individually or within a focus group, depending on preference and availability. 17 participants were recruited, all of whom met the inclusion criteria as detailed below:

#### Inclusion criteria

- People with a diagnosis of dementia according to the DSM-IV-TR criteria (American Psychiatric Association, 2000).
- Capacity to provide informed consent
- Able to communicate in English

#### OR

- People who identified themselves as an informal carer to a person with dementia.
- Capacity to provide informed consent
- Able to communicate in English

#### Data collection

Interviews followed a semi-structured format that allowed interviewers to ask spontaneous questions that addressed individual circumstances. This ensured sensitivity to participants' self-expression with regard to constructing his or her own accounts. Sessions were audio-recorded and discussion was facilitated around individual meanings and expectations of independence, social engagement, hope and resilience within dementia, the barriers and facilitators to these concepts and potentially related constructs including reciprocity. This enabled items to be developed that accounted for the individual differences of these concepts according to different participants.

People with dementia participated in two focus groups. However, due to the logistical difficulty in gathering members of carers in one space, individual interviews (some by telephone) were conducted with these participants. Examples of questions posed to both people with dementia and carers included: "Tell me about your (your relatives/friends) experience of independence?", "How has independence changed for you (your relative/friend/person you care for) since you began having memory problems?", "How have social relationships changed for you (the person you care for)?" and "How does having people around you benefit or hinder you (the person you care for)?" Focus groups and interviews lasted between 16 min and 35 min and were largely dependent on the carer's availability for individual interviews.

#### Data analysis

Thematic analyses are iterative in nature [9] and, to reflect this, transcripts were analysed by two researchers (CS and ML) independently. Initially, broad themes were generated to identify salient constructs. Following this, a consensus meeting was held in which researchers discussed their initial analyses. Any discrepancies between researchers were resolved through discussion. Once agreement was reached, both researchers' broad themes were synthesised into a table and refined into codes. The primary author and an independent researcher (CS and AS) then reviewed codes and disagreements were discussed until a consensus was reached. To limit researcher bias, data was independently reviewed and analytical notes of researchers own inferences were recorded. In this way, potential biases are documented and can be explored if necessary [10].

#### Stage 3: expert feedback and revisions

Draft outcome measures were then submitted to a panel of experts, who were asked to provide feedback and pay particular attention to item clarity, difficulty and relevance. Experts were also asked to delete items they felt inappropriate and add any additional items to ensure the domain to be measured was captured in its entirety.

#### Stage 4: pilot study

##### Design

A cross-sectional design was employed in which participants completed two newly developed outcome measures, alongside three other outcome measures. Participants could complete the study in a number of ways depending on their preference. Firstly, in a self-report fashion, without supervision. Secondly, in a self-report fashion, supported by a member of the research team. Finally, in an interview led manner.

#### Participants

Participants were recruited primarily through existing CST groups within a London NHS Foundation Trust and via private and voluntary organisations (e.g. CogsClubs). Four CST groups were contacted and, of these four, two took part in the current study. Ethical approval was granted and the study was adopted for portfolio. The facilitators of these groups (e.g. facilitators of CST groups) identified participants who they deemed eligible to meet the inclusion criteria:

- Diagnosis of dementia according to DSM-IV criteria (American Psychiatric Association, 2000).
- Capacity to give informed consent.

#### Procedure

The researcher initially approached organisations detailing the study to determine whether there might be interest in participation. If group facilitators felt there might be interest, a date to attend the group was arranged. In cases where this was not possible, the study was introduced to the participants by facilitators after they had received all information regarding the study.

Participants were provided with an information sheet and a consent form prior to data collection and informal capacity assessments were conducted with all participants. Four people who were approached were deemed to lack capacity and therefore were not included within the current research. The majority of participants elected to have the researcher present ( $n = 26$ ), hence, arrangements were made to visit participants at convenient dates and times. One CST group decided to complete the study during a break in a CST session ( $n = 4$ ). For this group, the researcher was present to assist, if needed, as they completed the questionnaires. Three participants elected to take the questionnaire pack home with them and return it via post. These participants were provided with a pre-stamped envelope and the work mobile phone number of a member of the research team, should they encounter any difficulty in returning or completing the questionnaires.

#### Analysis

Initially, the homogeneity of domains was tested for both measures using an internal consistency analysis [11]. Following this, convergent validity was assessed using a Pearson's correlation. Measures chosen to assess convergent validity were:

- Quality of Life in Alzheimer's Disease Scale (QoL-AD) [12]
- Geriatric Depression Scale SF (GDS) [13].

The QoL-AD was selected as some people able to complete it satisfactorily with a MMSE score of three

[14], it has established psychometric properties, is brief in nature and can be completed either in an interview or self-reported format. The GDS has been validated for people with dementia [15] and it is generally accepted that the GDS is an adequate tool to detect depression in people with mild to moderate dementia [16]. Due to the theoretical relationship between quality of life and positive psychology principles, it was hypothesised that a positive correlation would be observed between the PPOM, EID-Q and the QoL-AD. Positive psychology concepts may offer a protective effect against depression and, therefore, it was hypothesised that a negative correlation would be observed between the PPOM, EID-Q and the GDS.

## Results

### Stage 1: literature review

213 results were identified in which a number of positive concepts were explored. However, the majority of these papers were within the caregiving literature. Examples of qualitative studies reporting on people with dementia included a sense of coherence [17], spirituality [18] and hope [19]. A substantial review [20] of the qualitative literature indicated that resilience was particularly prominent within the qualitative literature, as did a qualitative study on the role of hope. Whilst independence and social engagement were discussed more sparingly and in the context of support or maintaining engagement with previously valued occupations, they may hold important implications for people with dementia. These concepts are discussed in more detail below.

#### *Sense of independence and social engagement*

The notion of a 'sense of independence' rarely appeared in the research literature. However, this may be particularly apt for people with dementia as they often face varying levels of independence within domains such as self-care, mobility and decision making and this can be influenced by how others treat them. More recently, retention of independence has been investigated as a valuable outcome for the maintenance of wellbeing for people with dementia. It can decrease the potential stress felt by carers and delay nursing home entry [21]. However, independence is often defined as a physical ability, for example, the time taken to walk from one place to another. This may be a simplistic view, which does not take into account more subjective views on what it means to be truly independent.

Independence may be closely related to social concepts including engaging with those around you and reciprocity. For example, people with dementia often require assistance from their carer or immediate family to maintain a level of independence they are comfortable with. As dementia progresses, a carer often assumes responsibility for tasks such as activities of daily living [22], financial decisions and advanced planning [23]. This relationship

is of paramount importance with a supportive relationship being linked to slower cognitive decline for the person with dementia [24]. It is, therefore, reasonable to suggest that independence for people with dementia may be very closely related and dependent on this relationship. No suitable measures were identified that examined a sense of independence and social engagement, and this may be because previously independence was purely examined as a functional capability. Due to the relationship between these concepts, the decision was made to develop one outcome measure and items were based on discussions in the focus group study.

#### *Resilience*

Resilience is often used to describe those who display emotional stamina in adverse situations. Its definition is sometimes ambiguous and therefore, the definition used in the current study will be the flexibility in response to changing situational demands [25]. It is noted that whilst some definitions refer explicitly to an adverse event preceding the development of resilience, the definition presented refers to changing situational demands as the precedent for resilience rather than an overtly negative event. Whilst it can be suggested that resilience is not an entirely positive construct, it is included in the current research due to its presence in a recent systematic review of living positively with dementia [26]. More specifically, this review of qualitative literature identified themes of engaging with dementia and 'facing it and fighting it' as a form of active perseverance through resilience. An earlier systematic review [26] identified four measures of resilience of varying quality. Of these, the Connor-Davidson Resilience Scale (CD-RISC) [27] was selected for adaption due to its thorough assessment of sensitivity to change and interpretability. However, the CD-RISC is a 25-item measure and, it was decided that this could be too time intensive. As such, the short form version (CD-RISC-SF) was examined and found to have adequate psychometric properties [28].

#### *Hope*

A substantial qualitative study examined the presence and conceptualisation of hope for people with dementia, for which their findings provide a strong rationale for the applicability of multidimensional hope, rather than goal directed hope [19]. For most, hope was described as an active process whereby a developmental history of 'learned hope' remains well preserved and this facilitated a process of 'keeping going', viewing difficulties encountered as challenges to overcome. Furthermore, there appeared to be an active re-appraisal of balancing hope and realism. This seemed to indicate that for people with dementia, outcomes hoped for are grounded in realism and generalised in nature, as illustrated by themes of



‘keep living and living well’ and this is consistent with studies of older adults without dementia [29]. Six outcome measures of hope were identified for possible adaption for people with dementia. These scales were then subjected to the Terwee Criteria; a tool for assessing the development procedure of outcome measures [30]. Of the six scales, two emerged as the most rigorously developed: The Hope and Coping in Recovery Measure [31] and the Herth Hope Index. [32] However, as the explicit focus was on hope, the Herth Hope Index was selected as the most appropriate for people with dementia.

Stage 2: focus group

As no measures of sense of independence and related social concepts were identified within stage 1, specific attention was paid to these concepts during focus groups and interviews. The total sample was 17, in which two focus groups for people with dementia were used (Group 1  $n = 3$ ; Group 2  $n = 6$ ) and individual interviews were employed for carers (Table 1).

Four overarching themes emerged as central to independence in dementia: 1) independence and interdependence, 2) functional independence, 3) remaining active and 4) social engagement. The first higher order theme illustrates ambiguity in definitions of independence in dementia and indicates that a period of interdependence between a carer and people with dementia can be beneficial for both. The second and third higher order themes reflect the differing domains within the construct of ‘independence’ and suggest that physical and mental ability may have important implications on the retention of independence. This was often compensated for with highly individualistic support provided by carers and a constant reappraisal of abilities and tasks as people with dementia’s ability to engage in such activities declined. The final higher order theme describes the retained desire of people with dementia to engage in social interaction with those around them and illustrates the barriers and facilitators to maintaining this engagement and its relatedness to sense of independence. These themes are discussed briefly below with selected quotes to support their applicability.

Table 1 Participant demographics

	Age M (SD)	Female n (%)	Ethnicity:	Caring for:
PwD <sup>a</sup> (n = 9)	80.56 (±7.13)	7 (77.8%)	Asian: 1 White: 8	n/a
Carer (n = 8)	n/a	0/8	Asian: 1 White: 7	Parent: 3 Spouse: 4 Grandparent: 1
TOTAL (n = 17)				

<sup>a</sup>Person with Dementia (PwD)

Independence and interdependence: definitions outside of and within dementia

Participants were initially asked to explore definitions of independence and this was often discussed by carers in the context of isolation from others: ‘I think it’s being able to do things by yourself maybe without the assistance of others or just being free to choose’ (C1). However, when asked to explore what constituted independence for people with dementia, definitions became more varied. Most prominently, participants felt that independence changed as ability to complete activities of daily living declined. This led to interdependence between a person with dementia and a carer. Examples of what this constituted appeared to be the giving of slight assistance to people with dementia so that they could maintain a level of independence that suited their individual ability: ‘Dressing and an occasional prompt... when the automatic is no longer automatic’ (C4).

Functional independence: activities of daily living, self-care and decision-making

Independence was discussed within the context of giving the ‘right’ level of support for a person with dementia. Too much could be frustrating for the person with dementia and too little could lead to the person with dementia feeling neglected. Carers often felt that, by adjusting the level of support given to a person with dementia based on their ability, it allowed people with dementia to focus on other decisions: ‘yeah just having sort of basic needs assisted with and then you’ve got extra energy to focus on some other things that might be a bit more challenging’ (C8). The potential for conflict occurred when the person with dementia felt that aspects of self-care were being taken out of their control but still appeared desirous to make a decision even if this was, as seen by the carer, the wrong decision: ‘If I say I don’t think you should... wear that... It’s not suitable for the weather. No he wants to wear it... if I don’t let go he’s very grumpy, upset’ (C2). People with dementia also displayed a retained desire and satisfaction in decision-making: ‘because I like to make decisions for myself...’ (P1)

Remaining active

Physical ability was implicitly related to maintaining a level of independence: ‘because I don’t go out... my legs. I like to go out and get on the bus to Romford... I couldn’t walk very far that’s the trouble with my legs’ (P5). As physical ability decreased, complex hobbies were often abandoned ‘I got plenty (of hobbies) but I can’t do them now’ (P3) and this could impact upon their sense of independence. An example of this came from a participant who discussed being no longer able to fish: ‘I’ve got to roll myself over to a spot so that I can



just get up and not join the fish... it's impossible' (P8), suggesting a close relationship between physical abilities and remaining active, and its impact on ability to remain independent. For carers, the need for people with dementia to engage in activities was seen as a form of mental stimulation, to delay dependence for as long as possible: 'It must keep the bits of her brain that are still functioning more active than they are currently and that just cannot be a bad thing' (C3).

#### **Social engagement**

Social concepts were often discussed in close relation with independence. For example: 'Being able to make decisions yourself without bothering anyone else but at the same time taking their problems into concern' (P1) and independent social engagement allowed people to feel they had accomplished much: 'we often say oh I'll pop out for an hour or so tonight...you feel fulfilled then at the end of the day and you don't need much if you're not talking about anything much' (P2). It was noted that people with dementia wanted varying levels of engagement and independently choosing their own level of engagement appeared to be the most beneficial: 'He was quite happy in a large pub where he could wander around and you know just chose who he would talk' (C1).

Reciprocity was seen by both people with dementia and carers as a means of being useful to a carer in ways that were manageable and was always discussed as an exchange of either activities or sentiment: 'Being kind to one another' (P1). A desire to give back was also explored by carers who were aware of the person with dementia's desire to be reciprocal with them: 'He knows that it would please me and it would make me happier if he helped. This is why he does it. I wouldn't say it's his hobby' (C2). However, when a person with dementia felt they could not be reciprocal, it could result in feelings of guilt and frustration: 'I mean bless his heart he says to me now I've ruined your life... he gets cheesed off at the fact his daughter is doing what I'm doing' (C5). This latter example was discussed within the context of a carer doing home improvement tasks around the house; something the person with dementia had been responsible for prior to the onset of dementia. This loss in autonomy resulted in friction within the relationship between the carer and person with dementia.

#### **Resilience and hope**

Saturation for resilience and hope data was reached very quickly. Resilience appeared to be present for people with dementia and was defined as: 'Take it as it comes unless you really clever and want to do something but I'm not' (P2). This attitude of taking life as it comes was discussed with regard to various hospital appointments and health problems. As such, health related resilience

might hold more importance than other aspects of resilience for this population and people with dementia noted the additional implications of ageing on health: 'The older you get the more difficult it becomes' (P1). In line with previous work, people with dementia viewed hope generally rather than situation specific and as being present on a day-to-day basis: 'Well I say I hope I get this and I hope I get that' (P1). The applicability of future oriented hope was also examined by one participant: 'I feel scared about my future but maybe I don't know if it's further down but just on a day-to-day you are... just worried about the day' (C2). This may be particularly relevant for people with dementia, as participants with dementia did not discuss future oriented hope.

#### **The EID-Q and PPOM**

Using the results of stage 1 and 2, 28-items were generated for the Engagement and Independence in Dementia Questionnaire (EID-Q). Due to the inter-relatedness of independence and social engagement, the decision was made to combine these concepts within one scale. As hope and resilience are more representative of positive psychology traditionally, The Herth Hope Index and CD-RISC-SF were combined and item wording was adapted to create the Positive Psychology Outcome Measure (PPOM).

#### **Stage 3: expert feedback and revisions**

Five experts from the Promoting Independence in Dementia (PRIDE) research programme responded to a request for feedback and revisions. Professions consisted of a professor of old age psychiatry, a reader in clinical psychology, a professor of community care research, a psychologist and a researcher. Results from all responders were pooled into one document using track changes and discussed within the supervisory team, until a consensus as to which suggestions to include as amendments was met. Most suggestions were acted upon to ensure an adequate level of content validity.

#### **EID-Q**

Responders noted three items that should be removed, as they didn't appear closely related to the concept in question. Examples of items removed included 'I feel connected to society'. It was suggested that other items were in need of rewording as they may be too difficult to understand. Six items were reworded to improve clarity. Examples included 'I can adapt my wishes to be in line with what I can do', which was replaced by 'I can make changes to my life to match my ability' and 'I can participate in a meaningful conversation', which was amended to 'I take part in conversations in ways that I enjoy'. No additional items were suggested but one responder did comment that the overall length might be excessive.

**PPOM**

Responders did not identify any redundant items within the PPOM but suggested that a number of items needed rewording to make them more appropriate for people with dementia. 9 items were reworded and examples included rewording 'I can see possibilities in the midst of difficulties' to 'I can see positive things in difficult situations' and 'I am able to adapt' to 'I am able to adapt to things'. Other items were suggested as in need of clarifying. For example, 'I am a strong person' was amended to 'I am an emotionally strong person'.

**Stage 4 pilot testing**

Thirty-eight people with dementia were approached to complete the novel measures and convergent validity measures. Of these, four lacked the capacity to consent and one declined to take part. This left a sample size of 33 (Table 2). All participants had been diagnosed with dementia and were deemed capable of giving informed consent. Eight participants elected to complete the measures in an interview led manner, whilst 25 elected to complete it in a self-report manner. All data was inputted into an SPSS file on a password-protected computer. Reverse items were recoded on the PPOM and EID-Q so that higher scores indicated a higher level of the domains assessed.

**Internal consistency**

**PPOM** The first internal consistency analysis revealed that the PPOM had an overall Cronbach alpha level of  $\alpha = .793$ , and the subscales were  $\alpha = .859$  for resilience and  $\alpha = .557$  for hope. This highlighted that one or more of the items on the hope subscale may not be pertinent for people with dementia. The resilience subscales' internal consistency was almost identical to the original, reported as  $\alpha = 0.85$  (Campbell-Sills & Stein, 2007) [24]. Following further analysis, it emerged that the removal of three items on the hope ('I feel all alone'; 'I have faith in the future'; 'I feel scared about the future';) subscale and two items on the resilience subscale ('I can achieve my goals'; 'I am not easily discouraged') would improve the internal consistency of the PPOM. After removing these items, the overall internal consistency improved to  $\alpha = .849$ , with the subscales improving to  $\alpha = .755$  for hope and  $\alpha = .871$  for resilience. This therefore resulted in a 16 item scale, consisting of a hope subscale (8 item) and resilience subscale (8 item).

**EID-Q** Initially the EID-Q had an adequate level of internal consistency ( $\alpha = .896$ ) and the subscales were also of sufficient value ( $\alpha = .849$  for independence and  $\alpha = .771$  for engagement). However, by removing one item from each subscale ('there are things I would like to

**Table 2** Participant characteristics

	Total
Gender <i>n</i> (%)	
Female	19 (57.6)
Male	14 (42.4)
Age <i>M</i> ( <i>SD</i> )	80.18 (8.27)
Marital status <i>n</i> (%)	
Married	14 (42.4)
Widowed	17 (51.5)
Divorced	2 (6.1)
Residing <i>n</i> (%)	
Community	30 (90.9)
Residential Facility	3 (9.2)
Ethnicity <i>n</i> (%)	
White (British)	28 (84.8)
White (other)	2 (6.1)
Black	1 (3)
Asian	2 (6.1)
Dementia diagnosis <i>n</i> (%)	
Alzheimer's Disease	13 (39.4)
Vascular Dementia	5 (15.2)
Dementia of mixed etiology	7 (21.2)
Unknown sub-type	8 (24.2)
Time since diagnosis <i>n</i> (%)	
< 1 year	8 (24.2)
1– 2 years	3 (9.1)
2– 3 years	8 (24.2)
> 3 years	6 (18.2)
Unknown	8 (24.2)
Cholinesterase inhibitors <i>n</i> (%)	
None	17 (51.5)
Donepezil	4 (12.1)
Memantine	6 (18.2)
Rivastigmine	3 (9.1)
Galantamine	2 (6.1)
Donepezil and Memantine	1 (3)
Other psychotropic medication <i>n</i> (%)	
None	27 (81.8)
Anti-depressant	6 (18.2)

do but can't; I have good relationships/friendships with others') internal consistency was raised to  $\alpha = .868$  for independence,  $\alpha = .775$  for social engagement and  $\alpha = .907$  for the scale overall. This resulted in a 26 item scale, consisting of an independence subscale (13 item) and engagement subscale (13 item).

### Convergent validity

**PPOM** Preliminary indications of convergent validity were found between the PPOM and the GDS. A two-tailed Pearson's R correlation found a significant, negative correlation between the PPOM and the GDS ( $r = -0.562, p = .002$ ) and the hope subscale and the GDS ( $r = -.557, p = .001$ ). However, the resilience subscale did not significantly correlate with GDS ( $r = -.312, p = .088$ ). An additional Pearson's R correlation was performed to assess the relationship between scores on the QoL-AD and the PPOM but no significant correlations were found.

**EID-Q** As with the PPOM, a two-tailed Pearson's R correlation was performed for both subscales and the EID-Q scale and the GDS. Significant correlations were found between the independence subscale ( $r = -.447, p = .012$ ) and GDS, the engagement subscale ( $r = -.430, p = .016$ ) and the GDS and the EID-Q and the GDS ( $r = -.461, p = .009$ ). This again indicates a negative correlation between the sense of independence, social engagement and depression. Pearson's R correlations between the EID-Q and the QoL-AD indicated an emerging positive relationship between independence, engagement and quality of life. Firstly, the total QoL-AD score was found to be positively correlated with the independence subscale ( $r = .497, p = .005$ ), engagement was correlated with the QoL-AD ( $r = .586, p = .001$ ) and the EID-Q was found to be positively correlated with the total QoL-AD score ( $r = .557, p = .001$ ) (Table 3).

### Discussion

#### Summary of results

This is, to our knowledge, the first study to report on the development of positive psychology outcome measures for people with dementia. The Positive Psychology Outcome Measure (PPOM) and the Engagement and Independence in Dementia Questionnaire (EID-Q) were developed using a robust four-stage procedure resulting in robust positive psychology outcome measures (Additional file 1). Potentially relevant concepts and related outcome measures were sourced and examined in the current literature. Content validity was provided during focus

group studies and expert revision. Finally, a small-scale pilot established adequate psychometric data for the new measures. The two new measures were easy to use and acceptable to participants, with most being able to give an informed opinion as to the use of these concepts in everyday life.

#### Findings in the context of the literature

Increasingly, the aim of psychosocial research for people with dementia is to maintain independence through interventions including exercise [33] and occupational therapy [34]. However, within these studies independence is defined in varying forms and usually as a functional ability, for example, the time taken to walk from one place to another or the ability to dress, both without the assistance from others. Whilst there appears to be an implicit expectation that improving independence will increase wellbeing, the observed relationship can be ambiguous [35]. The current study used definitions of independence as discussed by people with dementia in a qualitative setting and as such, the EID-Q is a more holistic measure of a sense of independence, rather than a measure of an operant capability.

The importance of the relationship between a person with dementia and their carer has previously been explored with a reciprocal relationship being highlighted as an important feature [36] and it has been proposed that reciprocity is a potential means of mitigating a loss of autonomy [37]. This reciprocal relationship refers to the ability of the person with dementia to provide assistance to their carer in ways that they feel are beneficial to them, in exchange for the carer providing means of assistance to them. Reciprocal relationships have been found to have numerous health benefits including reducing risk of stroke [38] and increasing psychological wellbeing for older adults [39].

Accounts of hope within the current study were consistent with previous findings in which future oriented hope appeared to be less appropriate for people with dementia [40] and accounts of resilience appeared to support the definition of adapting to changing situational and personal demands. Evidence for the relationship between hope and depression was also documented here and is consistent with the theory that positive psychology concepts may protect against depression [41, 42]. However no significant correlation was found between the PPOM and QoL-AD, possibly indicating hope and resilience may be distinct from quality of life.

Resilience as a positive psychology trait is not without issue. It is generally accepted that resilience is not a construct entirely characteristic of positive psychology but it was included within the current research due to its presence in the largest qualitative study of positive psychology and people with dementia to date [20]. Furthermore, positive psychology seeks to provide a balance and to exclude such a salient

**Table 3** Pearson's R correlations between measures

	GDS	QoL-AD
PPOM Total:	$r = -.562, p = .02$	-
PPOM: Hope	$r = -.557, p = .001$	-
PPOM: Resilience	$r = -.312, p = .088$	-
EID-Q Total	$r = -.461, p = .009$	$r = .557, p = .001$
EID-Q: Independence	$r = -.447, p = .012$	$r = .497, p = .005$
EID-Q: Engagement	$r = -.430, p = .016$	$r = .586, p = .001$



characteristic could leave to a tyranny of positives in which potentially beneficial concepts for wellbeing are not examined, because it is not seen as a completely positive trait.

Currently, there is a wealth of positive psychology outcome measures in use for other populations [43] but this approach is only just beginning to be applied to those with dementia research. There is an increasing recognition that positive factors can act as a protective agent in the development of negative emotional states including depression, and this has been exemplified in the dementia caregiving literature [44], where positive aspects of caregiving has been proposed as a buffer the negative consequences of caregiving such as depression, burnout and medical risk. The positive psychology approach to dementia reflects an asset-based standpoint, in which the retained capabilities and strengths that people with dementia exhibit are examined. These retained capabilities or strengths may be an important contributing factor to a person's wellbeing and interventions could be designed to bolster or maintain these strengths over time.

#### Methodological problems and limitations

Preliminary psychometric properties were established with a relatively small sample size, increasing the risk of a type II error. Also, the format in which measures were delivered may have impacted upon the instances of missing data. 25 participants elected to complete the measures in a self-report manner and these participants were more likely to miss items than those who completed the study in an interview led manner. This may have been a formatting issue or that participants felt unable to make judgments on particular items without guidance. Certainly within the interview led sample, participants struggled to answer future oriented questions within the hope subscale for the PPOM. This is supported by previous research in which goal oriented hope was found to be lacking for people with dementia [19]. Future oriented questions regarding hope were subsequently removed from the measure. Furthermore, it was noted that carers often had differing perspectives to people with dementia. This was particularly evident for the item 'I can look after myself as much as I need to' and it is unclear how much this affected the self-report sample.

We did not collect information with regard to cognition as the qualitative literature suggests that people with dementia experience these positive emotions throughout the course of dementia [20] and as such scores on a cognition test would not be relevant to these measures. However, all participants here had capacity to provide informed consent and so it can be assumed they were in the more mild stages of dementia. We therefore cannot make assumptions about the experience of positive emotions in later stages of dementia. This is something future researchers may wish to examine further.

Finally, it must be noted that a proportion of our participants were also receiving interventions including Cognitive Stimulation Therapy. These participants may differ slightly to those not engaging in activities but this is mitigated by the pilot study sample, for which participants who were not receiving an intervention were also involved. This limitation will be addressed in a further larger scale study.

#### Future research

As this study only provided tentative psychometric properties for the PPOM and EID-Q, the next stage is a larger study and further psychometric analysis, which is currently ongoing, and will allow the testing of the measures test-retest reliability, discriminant validity, factor structure and responsiveness. This will ensure that the developed measures can be applied within dementia services and research across the country.

Positive psychology is a broad discipline and there appears to be a need to formulate a theoretical model of this approach tailored specifically for dementia, to recognise the unique difficulties and capabilities this population has. This has, to some extent, been established within the caregiving literature with a focus on positive experiences of caregiving [45, 46] but is currently lacking within the dementia literature.

The evaluation of positive psychology concepts share difficulties with the appraisal of quality of life as it is argued that, below a certain level of function, people with dementia struggle to accurately appraise this [47]. Nevertheless, this study illustrates that, whilst positive psychology concepts require complicated appraisals, people with dementia appear able to give a view to this. As such, future quantitative research is needed to examine other concepts that may hold significance for people with dementia including love and humour.

#### Conclusion

Two positive psychology measures were developed using a robust, iterative process. The EID-Q and PPOM demonstrated acceptable internal consistency and convergent validity. However these psychometric properties were established using a small sample. Further psychometric analysis is needed before such measures can be used in psychosocial research to improve our knowledge and understanding of wellbeing for people with dementia.

#### Additional file

**Additional file 1:** The Engagement and Independence in Dementia Questionnaire (EIDQ) and Positive Psychology Outcome Measure (PPOM). Description of Data: The EID-Q (26-Item) and the PPOM (16-Item). Both are answered on a 5-point Likert scale, with a timescale of the previous month. (DOCX 107 kb)

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### Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

### Authors contributions

CS undertook data collection, data analysis and writing of the manuscript. MO commented on drafts of the paper, provided methodological support and supervised the study. ML undertook a section of data analysis and commented on drafts of the manuscript. EC commented on drafts of the paper and provided supervisory support. AS designed the study in collaboration with CS. AS also commented on drafts of the manuscript and provided supervisory support. All authors read and approved the final manuscript.

### Competing interests

The authors declare that they have no competing interests.

### Consent for publication

Not applicable.

### Ethics approval and consent to participate

Ethical approval for the current study was granted in two parts. Firstly, as part of the Promoting Independence in Dementia research programme (15/EE/0134) at the East of England Research Ethics Committee (REC) and secondly as part of an individual PhD study (15/EE/0443), again at the East of England REC. All participants who participated were deemed capable of providing informed consent and were required to sign a consent form.

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## 6. Participant Feedback

Some details have been removed to protect confidentiality of participants.

### 6.1 Example of positive feedback (PPOM)

*“Friday saw a visit from (RA name) from the local clinical research network team as I’d agreed to take part in another study. The week had felt a busy one, so it was nice to have RA come to my house so I didn’t have to go anywhere. I’ve said in the past how I love to be involved with students as they can change how dementia is portrayed in the future. They’re also like a sponge soaking up everything you say. So the reason I said yes to this one off interview is because it’s part of a student’s PhD project – Charlotte from the UCL – is trying to understand how personal strengths contribute to well being. Things like hope, independence, resilience and how they can impact on quality of life. 2 new sets of questions have been developed and they’re being tested to compare to existing questionnaires. The questions were all around how you feel about yourself and your situation. I assume and hope that Charlotte will get feedback from people with dementia around the questions as I’m sure this will provide extra evidence and thoughts around the type of questions we’re asked and the effect they have on us when answering.....”*

### 6.2 Feedback denoting methodological issues (PPOM)

*“I suspect that this is down to me not having experience in doing anything like this. However, when we did the first one, I read them out in quite a flat, neutral tone of voice (I didn’t want to influence her answers), which she responded to OK. The second time, I used a more ‘engaging’ tone of voice when I asked, as though we were having a ‘proper’ conversation and that worked much better. Also, I found that sometimes, the ‘I’ in the question made her think I was talking about me, so I used ‘you’ instead and that*

*seemed to help a lot. She has always had an incredibly positive outlook on life. She never accepted the fact that she has Alzheimer's but is happy to put things down to 'being very old' (93). I'm learning so much about her, the disease (is it a disease?), and myself as we go through all of this. It's challenging, but hugely rewarding as well. Oh yes, another thing was that she didn't really understand the different categories from very high to very low etc., so I had to do a bit of interpretation... for example, whenever she exclaimed oh yes! or oh no! I took that as a 'very'. A slight wavering in the 'yes' or 'no' was the next level down / up. 'More or less' was somewhere in the middle. I don't think it was too 'unscientific' though as it was pretty easy to work out the level from her response".*

### **6.3 Example of negative feedback (PPOM)**

*"Just think you ought to be aware of what happened the Friday after you saw Dad, [daughter] said that the questionnaire covered a lot about work. I think it must have put it in his mind, as the next day he set off around 9.30am to drive to (town name), where he used to work and live, followed by (town name), (town name) and (town name). I had a phone call from the police at 2.30am Saturday morning after they stopped him travelling the wrong way down the fast lane of the (motorway), in the (area name). I think he had been trying to get to the (name of work place) where he also used to work in the 1960s, when he was stopped. Fortunately there were no accidents, but obviously he can't drive any more. The timing could be coincidental, but I don't think so, so maybe this needs to be fed back into the research that asking these kind of questions can be quite disruptive to a person with Alzheimers, unsettling them, and setting them off to seek something they no longer have, such as fulfilling work. What do you think?"*